Telling our stories: What my urban, multiply-challenged deaf and hard of hearing students taught me about ability, schooling, and learning to teach.

A DISSERTATION
SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL
OF THE UNIVERSITY OF MINNESOTA
BY

Lisa Dembouski

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

Mistilina Sato, Adviser

October, 2010

Acknowledgements

I extend my highest and most sincere gratitude to:

Misty: who graciously accepted my awkward and, ahem, unconventional request to be my adviser on the city bus ride we shared that day; was always a thorough and careful reader; is a generous and exceptional host; and always knew what I was trying to say (and could help me find the words I needed to say them, usually far better than I could have imagined). And look! As promised! I didn't use "extant" even *once*!

Tim: for championing peace, equity, and alternatives. Plus, you read the entire thing when you didn't even have to!

Bic: for always challenging my thinking and getting me to articulate exactly what I meant and why I thought the way I did.

Jim: A voice for aesthetics and my Narrative Inquiry champion in the sometimes-lonely and darker corners of narrative research.

John: My D/HH expert from the days of my student teaching all the way through to this research and dissertation. You have been generous since the very beginning.

My fellow graduate and CaT students who seemed to support and understand at every turn. I extend special woots to the Other Two Amigas and my trusty ERBanites whose kind hearts, sharp eyes, and gentle revision suggestions were beyond helpful.

Joel who, from the minute I mentioned the fool notion of attempting a PhD, has most frequently said, "How can I help support your doing this?" and who swears that, even knowing what he knows now, would still encourage me to go for it. I am exceptionally fortunate.

Maisy and Melli, who reminded me on those occasions I forgot to take time for affectionate attention and for proving definitively there is room enough on my lap for a cat *and* a computer!

Thomas for his friendship and vision; and my colleagues at Cosmos and River City Schools who work so hard in rarely-favorable climates.

My friends and family for tolerating my absences from just about everything for the past five years; I'm more available now!

Dedication

This dissertation is dedicated to
Cameron (October 24, 1984 – August 30, 2010)
How grateful I am for your gifts, even after you have gone.

Abstract

This study is a critical narrative inquiry. The participants are my former pupils: graduates of an urban secondary program for multiply-challenged deaf and hard of hearing students. The researcher is me, their hard of hearing teacher who, as a result of her time in the classroom with these individuals, started to ask a lot of questions and then set out to answer them. All of us, our lives, and our stories, are the heart and soul of this study.

Through the theoretical, epistemological, and methodological lenses of narrative researcher, theorist on social justice issues, and special educator I inquire into the lived experiences and resultant stories of my former students. I place particular emphasis on using participants' voices that, in most other arenas, are seldom heard. This study also explores ways my participants taught me to better understand ability, schooling, and learning to teach and how we might re-imagine these constructs and institutions in the years to come. Finally, this study considers ways our stories may contribute to education for similar individuals and ways our voices might expand what is understood in our field.

Table of Contents

List of Tables

Participants' Preface

We cannot choose where to start and stop.
Our stories are the tellers of us. – Chris Cleave

As I was writing the pages you are now reading an unexpected and perplexing issue slowly arose. "Where," I wondered, "do I put the kids?" I had dozens of stories told to me (and just as many more of my own); pages and pages of interview notes; boxes of artifacts I had saved from our years together in the classroom; and dissertation-ready descriptive introductions written for all of "the kids," that is, my former students who I interviewed for this study. Somehow, though, I could never find the place to actually insert those introductions.

Finally, late into an insomnia-filled night, it came to me: they must be at the very beginning. My research participants are graduates from the program where I teach; they are the urban, multiply-challenged, and deaf or hard of hearing (MCDHH) individuals identified in the title of this writing. My participants are also the reason I started asking the questions that frame this study, including: *What are the lived experiences and resultant stories of MCDHH individuals? How can I give these students' voices a venue in which they will be heard? What have my students taught me about ways of understanding ability, schooling, and learning to teach? What can our stories contribute to the field of deaf/hard of hearing education? How would our field change if our stories were told?* My students (past and present) are the reason I embarked upon this study in the first place, so they must be where it all begins.

Angel

> My name[1] is Angel. I am from Somalia, the city of Mogadishu. I was born and raised in Mogadishu, but moved to Kenya when I was 13 years old. For two years we lived in Kenya. There my family did not live in nice conditions; we were always wet, dirty. My older siblings decided they wanted to come to the U.S. We filled out the paperwork for this and then we arrived here in 2001. I was 15 [years old]. It was February then, and the first time I wore shoes that were not sandals. It was really cold and icy here; we didn't have the right clothes. Wow!
>
> When I started school, it was the first time I ever attended a school. It was at Cosmos High. I was 15 years old. I was shy. I didn't know any ASL (American Sign Language). I didn't know anything, how to do anything, how to sign, how to write, nothing.

Angel was 24 years old at the time of our interview and had graduated from Cosmos four years earlier. Though she speaks of moving to Kenya in her early teens, she does not explain that this move was to a refugee camp as a result of the Somali civil war. It could be that Angel does not have the language for these realities. Or she may not understand that "moving to Kenya" was a life or death necessity given her limited ability to communicate with her mother and siblings. Angel never mentions her father and his whereabouts are unknown.

Angel is deaf and communicates with her family through speechreading[2] her home language of Somali. Her primary mode of communication here in the United States is ASL. She also uses written English. Angel moved to the U. S. as an adolescent so, according to Roberge (2003), is considered a 1.5 generation immigrant. In addition to her deafness, Angel's multiple challenges include delays in language acquisition (because of her hearing loss she has never been fluent in her home language of Somali; she was not exposed to ASL or a signed language until age 15); no formal educational opportunities until her mid-teens; severe economic needs; a home language other than English; cultural marginalization and minoritizing due to her race, ethnicity, and Muslim religion; and limited communication between herself and her family members who have not learned to sign.

Cameron

Cameron did not give me an interview like the ones I had with my other study participants. I did not ask him any of my prepared questions and was unable to communicate with him the way I once could when he was a student at Cosmos. Cameron's stories fill the pages of chapter five, so I will keep his introduction brief.

Cameron is a 25 year old African American; he was born and raised in the U. S. He currently lives in the suburbs, in a group home for multiple needs adults. He attends a day program that provides supervised work experiences in community-based jobsites as well as weekly leisure activities like an afternoon at the zoo. Cameron has multiple medical issues that leave him quite physically fragile. He is deaf and communicates through ASL. In addition to his hearing loss and medical fragility, Cameron also lives with cognitive delays; cultural marginalization and minoritizing due to his race and ethnicity; and severe, persistent communication challenges because no one in his group home can sign proficiently.

Choi

> Years ago I made many friends; I met, got to know, and connected with many people. I graduated from high school in 2001. Now I'm old, 27 years old. (Here Choi actually signed the month, day, and year of his birth. I missed the year, however, and asked him to repeat it so I could accurately record his age. Rather than give me just the year of his birth, though, he repeated the entire sequence of information. This indicates he might only know his birth date by rote.)
>
> I was born in Laos and moved to the U.S. when I was 11. We first arrived in California, but then we came here [to River City]. My brother and I have stayed here ever since, but my parents do not live here now; they are in another state.
>
> I would like to travel more, see more places, go to the park or go camping. Travel is too hard to do, though, because the cost of the tickets is very strict [prohibitive]!

Choi is deaf and communicates exclusively through ASL and written English, though he does neither proficiently and was the most difficult of my participants to interpret. He makes multiple errors and signs rapidly as well as nonsensically, so I had to ask him clarifying questions or to repeat things he had said throughout our interview.

Though he claims his brother can "interpret" for him and help make his messages understood, I do not know how fully he communicates with members of his family in their home languages, English and Lao. Since Choi was born in Laos and moved here as an older child, he is also considered a 1.5 generation immigrant to the United States.

Choi did not receive any formal education until his arrival in the U. S. His multiple challenges include poor or limited communication between himself and others; delays in language acquisition (he did not know or use a language until he came to the U.S. and learned ASL) resulting in limited linguistic skills; no formal schooling prior to his arrival in the U. S.; economic disadvantage; cultural marginalization and minoritizing due to his race and ethnicity; and suspected learning disabilities.[3]

Daniel

> I'm 19 (later in the interview he amended this statement when he realized he was actually 20 years old at the time we met). I'm from (a state in the Midwest). I like to have fun. I love my friends and family and shopping a lot. I like going out clubbing. When I'm not with my friends I usually stay home and chill with my family. I like to cook and sometimes to swim. I make time for myself. I work at a Mexican

> restaurant. I'm very energetic; I'm crazy and goofy and I like to have fun. Sometimes I'm willing to try new stuff; I'll be scared, but I'll do it. I'm very open-minded. I help people out if they need it. I like volunteering. Also, I love animals and my pets.

Daniel was the first graduate I interviewed and my reasons for this were deliberate: I needed someone I knew would be "easy." What I mean is, when it came time to begin conducting this study, I found myself putting off scheduling the interviews. I realized this was because I was afraid I did not know how to do them or how to be a "proper researcher." Here it was, my big study, the research that was going to give me my doctoral dissertation, and I was afraid I was going to mess it up, not do things "correctly." To get past this personal barrier, I needed to choose a former student with whom I had a good rapport and Daniel was definitely that person. He and I have a positive student-teacher relationship and I knew his would be an interesting, genuine interview. I was not mistaken. Daniel was a true gift for me; without him, I may never have climbed over my fear and into the current of this study.

Daniel is hard of hearing. He communicates with either spoken/written English or a combination of English and sign language (used simultaneously), depending on the circumstances and his audience. He graduated from Cosmos the year before our interview. Daniel is Chicano; he was born and raised in the city where he lives now. English is his home language. His multiple challenges include cultural marginalization and minoritizing due to his race, sexuality, and ethnicity; economic disadvantage; and suspected learning disabilities.

DJ

> I was born in America in 1981. I grew up at Lake Elementary. I went to Cosmos (his high school); graduated in 1998 when I was 21. I lived with my mom, stepdad, and two siblings from their marriage. My mom divorced my [biological] father and he lives in Chicago. I lived in River City the whole time [growing up].
>
> Elementary school was easy, I played and had fun. But it also was not good because people picked on me and [the academics] were hard, writing and stuff, I didn't understand. The sign language and everything else took me longer. Cosmos was better because elementary school was frustrating and hard but at Cosmos I started to understand and passed my classes instead of always failing.

You may have noticed DJ's numerical information is contradictory; if he was born in 1981 and graduated in 1998, he would have been 17 years old at the time of graduation, though he says he was 21 that year. My recollection is that DJ stayed on at Cosmos as a "super senior" (students in special education may remain in school through age 21) and did graduate later than age 17, so it is likely he mistakenly reported the year he graduated but was correct about his age at the time of graduation.

DJ's use of the past tense when speaking about his family and growing up is because he now lives in a group home for nonverbal adults with developmental delays; I met some of his housemates during our interview. DJ is deaf and communicates through

ASL or written English. He is African American. He was 29 years old at the time of our interview. English is his home language. DJ's multiple challenges include the educative disabilities of deafness, cerebral palsy, and cognitive delays; cultural marginalization and minoritizing due to his race and ethnicity; economic disadvantage; and poor or limited communication in the home because his family members do not sign fluently.

Ken

> I was born and raised in River City. I was born in 1998. I graduated from Cosmos in 2007. I have four sisters and one brother, I am the oldest. The sister just after me is married and doesn't live in our house, but the rest of us (live there).
>
> My goals are to move to an apartment and live independently. I want to take driver's education again. I can't see, so I need to get glasses. I'm looking for a job; I will clean or do stocking or whatever. I'd like to get married. I'll probably stay here (in his current state of residence) to live, but I'd like to travel, take vacations.

Ken's interview was, for me, one of the more unsettling. For one thing, he was very different from the person I once knew him to be. In the old days, he was somewhat naïve and always seemed younger than his years. He was also usually quite transparent, what he was thinking or feeling was almost always very evident on his face or through his body language. The young man sitting across from me during this interview, though, was none of those things. He seemed much more guarded, much less readable, and no longer gave off those "younger than his years" vibrations. I could not quite put my finger on what was so different, but going through my notes later I realized I had written several descriptions about his appearance and features such as "Why does Ken appear *so tall?*" I imagine these comments and questions were ways my mind was working to explain Ken's transformation.

Ken is Hmong American (2nd generation Hmong; he was born in the Midwest, his parents emigrated from Laos before he or any of his siblings were born). Ken was 22 years old at the time of our interview. He communicates almost exclusively through ASL. He can also use written English, but only minimally as his skills in English are not strong. His family speaks Hmong in the home. Ken's multiple challenges include cultural marginalization and minoritizing due to his race and ethnicity; cognitive delay; economic disadvantage; a home language other than English; and limited communication in the home since no one there signs fluently.

Scooter

> I like to play sports: baseball, floor hockey, bowling. I like to watch movies. My personality is good. I'm generally positive. I was born and raised in River City. I live with my mom, stepdad, and younger brother. I am 31 years old.
>
> My friends and I go out. We like the mall, going to the movies. I enjoy that. My brother is teaching me how to draw. I say "It's hard," but he

> shows me what to do. Now I can draw things like mushrooms, men, cartoon faces; I enjoy that, too.

Scooter is deaf. He communicates primarily through ASL and written English. He is European American. His home language is English. Scooter once lived in the same group home as DJ, but his mother did not believe he was receiving adequate services or care in that setting so she moved him back into her home. Scooter's account for the move is that "the staff bothered me so I moved back with my family." He did not elaborate on what "bothered me" actually entailed and I did not ask because I was captivated by the next part of his statement, "Did you know I ran away from the group home once?" and I got caught up in that story instead.

My interview with Scooter was pleasant and entertaining because he was personable, friendly, and clearly enjoying himself; his mood was infectious! Scooter, more than any of my other participants, took advantage of my connection with his former classmates and shared lots of gossip, asked a number of questions about his friends and their whereabouts, and often demonstrated very strong feelings about people who are unkind or seem to enjoy causing problems between people. He appeared quite tied to "what is right" and displayed a strong dislike for individuals who bring meanness or trouble into the world.

Scooter's multiple challenges include economic disadvantage; educative disabilities including hearing loss, cerebral palsy, and cognitive delay; and challenges at communicating in the home since his mother has rudimentary sign language skills.

Sky

> I was born in [a Midwestern city] in 1989. My family moved to [a River City neighborhood] when I was two years old; I have lived here ever since. I live with my parents, a brother, and two sisters.

My open-ended introductory question to "tell me anything about who you are" was hit or miss with my participants and with Sky it was a terrible "miss." I tried to explain and reword it several times, but each time she simply smiled and shrugged. I am not sure if she was confused by the question or was unwilling to answer it and tell me about her self-perceptions, her interests, or other personal information. My memory of her as a student is similar in that, with adults, she was rarely forthcoming about herself or her personal life and typically only shared such information with a select group of trusted peers.

Perhaps my recollection of who Sky used to be prevented me from probing further or inquiring more; I may have assumed she would be as reserved now as she had been when she was my student. In retrospect, my failure to better understand Sky and who she is now could be a consequence of moving from teacher (known, more familiar to me) to researcher (less known or practiced compared with my teaching history). It seems that, as happened with many of my graduates during their interviews, my automatic response was to act as a teacher, even when I was in the middle of researching.

Sky is a 2nd generation Hmong American. She was 21 years old at the time of our interview. Her maternal grandfather is deaf; her maternal grandmother is hard of hearing, so her mother is a kind of CODA[4]. English, Hmong, and sign language are all used in Sky's home and throughout her extended family. Her multiple challenges include cultural marginalization and minoritizing due to her race and ethnicity and suspected learning disabilities.

Sweet Girl

> My name is Sweet Girl. I live here in [a River City suburb]. My group home is called "The White House" because it's white. It's like the president's house, but also not (here she smiles at her own joke and waits for me to appreciate it as well before moving on).
>
> I worked for five and a half years for [a supervised, community work organization]. Before that, I worked at [a private business, a salon and spa chain], but I was laid off in 2009 after working there for seven years. It was a good job, it was professional and they really liked me there; they were proud of me.
>
> Now I work at [a retail clothing store]. I wanted a job where I could show my independence and my work skills. At this job I clean and vacuum, organize shelves, move and put away incorrectly-placed items; like, I keep the same sizes all together. I basically neaten and organize. I also clean the bathrooms. I work Monday through Friday,

> two hours a day. My job coach told me that soon, this spring, my hours will increase to four per day.
>
> I was born in the Philippines in 1981. I moved to the U.S. when I was 12 years old. My parents divorced. My mom had a drinking problem; she couldn't take care of herself much less her kids, so my brother and I were moved to foster care. We lived in River City and I went to Lake Elementary, [I started in] the fifth grade. That's also where I began to learn sign language. I remember speaking English more than any other language.

As you can see, Sweet Girl strongly identifies with her vocational life; she spent a great deal of time explaining the different work she has done and primarily used those experiences to reply to the "tell me about yourself" interview prompt. She also remembers very little about her years in the Philippines and most of her memories seem to begin here in the U.S. For example, she does not recall speaking any language other than English even when Filipino is the principal language of the Philippines and her parents, both natives of Cambodia, likely spoke Cambodian in the home. She is another of my graduates who is considered a 1.5 generation immigrant.

Sweet Girl is hard of hearing but primarily communicates with ASL; occasionally, if it will make others understand her better, she will also speak. She uses written English as well. Her multiple challenges involve some of the family issues named above (there are more than what she recounted including an abusive father and being given away as a ward of the state when she was 14 years old); economic disadvantage; severely delayed language acquisition; no known formal educational experiences prior to her arrival in the U. S.; cultural marginalization and minoritizing due to her race and ethnicity; complicated health concerns including physical and other health disabilities (cerebral palsy, severe Type I diabetes); and cognitive delays.

Vue Pao

> My name is Vue Pao. This is my first year at [a transition program he enrolled in upon graduation from Cosmos]; I'm really enjoying it. I'm making lots of job experiences, three different ones so far. I really enjoy it! I'm also liking my new friends who are from Cosmos and other schools. I like my staffs and people like my job coach who are really nice.
>
> There was one time that I feel a little bad about with my job coach … sometimes they are nice to me and sometimes mean to me. They were mean like, keep making me upset sometimes because they would yell and I don't like that. I do a really good job, really good job. My job coach is really proud of me. It's only job training, not a paid job yet. I don't know if I will get a paid job or not, but this year is only training. Next year maybe a paid one, I'm not sure yet.

> My family they really like this place (the transition program), they're really happy to have me here and to learn job skills. I mostly learn job skills here, but I don't know if I'm going to learn other things. I'm learning a lot about different work tasks like recycling, cleaning, taking out trash.
>
> I speak Hmong sometimes, but mostly English. I speak Hmong to my friends, and at home I speak Hmong too. My brother, he went to Laos, to pick his wife and bring her to the U. S. He'll be home soon, March 30, at the end of the month. I haven't talked to him since he left on March six. He went to pick his wife, he didn't know her before that. We're really excited about that. They will live with me and my parents. It (the family home) should be big enough; I still live at the same house you saw. We talked about moving, but it's too hard for us, the paperwork.

Vue Pao, more than any other study participant, was most inclined to express himself and his ideas through stories. He frequently began a sentence or started to share a thought, then would launch into active storytelling to make his point or further develop his ideas. Later, when I reviewed the notes from our interview and realized how often our conversation included stories, I recalled this had been true for Vue Pao in the classroom as well. I admit I was not always as receptive to his drawn-out tales then. In those days, I more often had some agenda about a lesson or curricular point I "needed" to make and did not appreciate Vue Pao’s narratives for what they were: an exceptional way of making himself understood.

Vue Pao is a 1.5 generation Hmong American. He was born in a Thai refugee camp called Ban Vinai and immigrated to the United States in 1993 at the age of three. His parents are older and neither work outside the home; the family relies on Supplemental Security Income (SSI) and whatever his father can trade or barter for his shaman services in the Hmong community. As he stated, Vue Pao uses both Hmong and English and is equally strong—although not fluent or proficient—in both languages. He is hard of hearing and never learned to sign, though he can hold very basic conversations with his deaf peers. His multiple challenges include economic disadvantage; cultural marginalization and minoritizing due to his race and ethnicity; and cognitive delay.

You will get to know the ten individuals introduced above much more as this writing progresses. I have known most of them for at least a decade; each has taught me a great deal in that time. They continue to teach me still, which is what this dissertation is all about. In this work I will use a combination of their voices, plus my knowledge of who they are and how I have interacted with them over the years, to tell you more about them and the things they have taught me. I will also present them to you through my lenses as a doctoral student of Culture and Teaching, an insider-outsider to their lives and cultures in an urban classroom for multiply-challenged deaf and hard of hearing children, and my utter conviction that critical narrative research with this participant population is long overdue.

Endnotes

[1] All names are self-selected pseudonyms with the exception of Cameron, whose pseudonym I created.

[2] While the term “lip reading” is regularly used to describe this form of receptive communication, “speech reading” is more accurate in describing what actually takes place. Very little verbal information is available by reading lips alone: watch yourself in the mirror while you silently mouth the words “marry me” and “bury me”—they look identical yet, of course, convey very different meanings! Speech readers therefore use contextual cues as well as any available visual information like the speaker’s facial expression or body language to make sense of what is being said.

[3] I use the term “suspected learning disabilities” because diagnosing or “proving” learning disabilities in deaf or hard of hearing students is highly problematic. One reason for this is because the education and learning challenges that can arise from a hearing loss frequently resemble the challenges that are caused by learning disabilities (Spencer & Marschark, 2010).

[4] The acronym CODA stands for “Child/ren Of Deaf Adults” and most commonly refers to hearing children who have deaf parents. Though they are hearing and therefore have access to spoken language, CODAs’ first language is usually one that is signed.

Chapter 1: Speaking Our Truths

Speak your truth quietly and clearly;
and listen to others…
they too have their story. – Max Ehrmann

The start of this first chapter allows me to introduce a writing convention I intend to employ throughout this work: different fonts or typefaces for different voices. As you saw in the Participants' Preface, I use the Century font to represent my participants' narratives. I will use the Tahoma font when telling my stories or recollections, and the Times New Roman font for everything else. I hope this additional demarcation creates extra strength and resonance for all of our voices.

Beginning with My Story

I read someplace that by the time a person from my generation[1] reaches retirement they will have had at least seven very distinct career experiences. As much as I wish I was different from everyone else, this statistic will probably be true for me, too. In addition to the jobs of my youth like group home staff member and restaurant server, I have been a mental illness day treatment worker, a health educator with the Peace Corps, and a wilderness survival counselor at a year-round corrections camp. Additionally and, perhaps, most importantly, I have spent the last decade as a teacher of the deaf/hard of hearing (D/HH) in a large, urban, Midwestern public school district I will call River City Schools.

I got into the general field of education because I like to get paid for being who I am and teaching comes fairly naturally to me. I am in D/HH education specifically because, in my 20s, I lost most of my own hearing to the unflinchingly cruel Meniere's disease; I needed to find a career where it wouldn't matter if I could hear or not.

My first few years in the classroom flew through the blur of steep learning curves, the thrill of discovering my practice, struggles to gain sign language fluency, and my delight with unusual children who are, without question, my favorite part of teaching. Time passed and I became more familiar with what had been barely-navigable paperwork and policy expectations. Now I was able to look around, be more reflective about my practice, and I realized that my students were repeatedly showing me something I was uncomfortable seeing: I had not been adequately prepared to teach them. Not even close.

It is important to note that all of my students have both a hearing loss (itself a substantial complication for teaching and learning) as well as a variety of other special needs, exceptionalities, or challenges including co-occurring educative disabilities, extreme delays in language acquisition, limited (or no) previous experiences with schooling, severe economic needs, a home language other than English (which is more relevant for the hard of hearing students), minority race and ethnicity barriers, or an inability to communicate with anyone in the home because they are deaf and their family members have not learned to sign. Students like mine are sometimes referred to as “inner city deaf,” “lower achieving and multiply disabled deaf,” “minority ethnic deaf people,” “deaf students with multiple disabilities,” and, in the earlier days (though not so long ago), “hearing-impaired students with multiple disabilities,” “low-functioning deaf,” and "multihandicapped hearing-impaired" (Bowe, 1972; Bowe, 2002; D'Zamko, & Hampton, 1985; Ewing & Jones, 2003; Jones, 1984; Reiman, Bullis, & Davis, 1992; Rodda & Eleweke, 2002; Wheeler-Scruggs, 2002; Whelan & Kretschmer, 1996). I choose to represent these individuals and their differences a bit more holistically and, when I must refer to them collectively, use the term "multiply-challenged deaf/hard of hearing" (MCDHH) not to define them as such, but to illustrate some of their everyday realities.

Imagine for a moment: what might it be like for Scooter to comprehend something through the haze of a hearing loss *and* a cognitive delay? How did Angel think before she was given her first useable language at age 15? What occupied and engaged Choi all day while his siblings were in a school he could not attend because he did not talk? If your mother does not know the words you use, to whom do you go when you are scared? Or when you want to share a dream?

These are the existential truths for the kids who charm me utterly, the ones who make it easy to wake up at unholy hours to be with every day, and these are the same children who are consistently overlooked and underserved in my field of deaf and hard of hearing (D/HH) education (Johnson, 2004; Luckner & Carter, 2001). I thus returned to graduate school with bewilderment and an agenda: to figure out how we might *stop* ignoring MCDHHH students and how we can better prepare their teachers who will, inevitably, find such a child in their classroom one day (Luckner & Carter, 2001; Spencer & Marschark, 2010).

While I am still devoted to these topics, my interests in critical theory and justice pedagogies have expanded my field of vision to include other pursuits, of which narrative is now a part. I hope this narrative inquiry can be both a window into worlds like the ones my participants inhabit and a mirror for the educators who also know students like mine. While before I wondered what it would be like for Angel to think without a language, now I wonder what would happen if instead we could tell Angel's stories. What would it be like to hear the voices that few have listened to before? How did my working alongside these students shape my teaching practice and how might the same be true for other teachers? How would my field change if our stories (my students' stories as well as my own) were told? These are the questions I seek to answer in the chapters to come. This work reflects my efforts to move MCDHH people out of the margins and into the center; they will be the focus of this writing. First, allow me to provide the necessary contexts for our stories by introducing you to the setting, program, participants, and researcher of this study.

The Setting

Cosmos High

Politics and Policies. Ten years and three superintendents ago, Cosmos, in a tornadic maelstrom of "school reform" was one of nearly a dozen River City Schools placed "on probation." This event, enacted as part of the freshman superintendent's ambitious and attention-getting entrance into district leadership, has left an indelible mark on Cosmos. What had been a positive work environment full of (mostly) dedicated, enthusiastic educators overnight turned somber; a place where conversations became more muted, suspicious and blaming fingers were aimed, alliances were formed. It made a deep impression on me, an untenured teacher, who never imagined that working in a school would be so much like attending one: always under the watchful—and disapproving—eye of authority. In disenchanted mockery of those "My Child is on the Honor Roll at Awesome Secondary School" bumper stickers, Cosmos' own sticker appeared, shared only with the most trustworthy among us: "My Kid's on Academic Probation at Cosmos High."

The people I admired as strong and skillful educators were now suspect, supervised closely, chafing at the loss of academic freedom and the pursuit of their practice. Many of them left, citing intolerable work conditions. To me it seemed that the less skilled educators, those who had been there for decades, had long ago stopped caring and did not really notice a change. They remained at Cosmos, living out their days until retirement, doing pretty much what they had done all along, unconcerned with the tempest swirling around them.

The rest of us, those not in the field long enough to be master educators, yet not so long to have grown apathetic (as I think some teachers do), felt the weight of the new label and the responsibility for our students' perceived failures like a leaden cloak. The burden has never since been lifted from our shoulders.

After "academic probation" stunned the building, No Child Left Behind (NCLB, 2003) swept the nation as the George W. Bush Administration's grand plan for academic accountability. Under NCLB, Cosmos was regularly identified as a school that failed to demonstrate AYP or "adequate yearly progress." This label was determined by various numerical indicators like graduation rates, daily student attendance, and scores on standardized "high stakes" tests. So while the names were somewhat changed, the messages remained the same: Cosmos was not making the grade and the primary players under fire once again were teachers. Extreme measures at “school restructuring” have been implemented over the past several years; most of them dictated top-down fashion by district administration. Despite the criteria used to determine schools’ AYP status, most of the actions taken toward “restructuring” at Cosmos did not target those criteria. For example, student incentives for regular attendance or support and guidance toward achieving the necessary number of credits to graduate were never included in restructuring decisions. Rather, the changes primarily involved Cosmos personnel: nearly *all* of the teachers in both the science and social studies departments were transferred to other schools in the district and new faculty brought on board to replace them. Curiously, the teachers in the English and math departments remained mostly intact, even though Cosmos students have consistently failed to make AYP for those subjects. The reasons for dismantling the staff in content areas that are not tested have never been explained.

Now, under the Obama Administration, and with literally no time allowed for the earlier reforms and restructurings to take hold or demonstrate change, Cosmos has been targeted once again. This time River City Schools intends to send Cosmos through another obstacle course of educational reform under an opaque “School Improvement Grant” to be implemented in the 2010-2011 school year. None of the conditions of this grant have been fully explained to Cosmos administrators or staff, but there are early whispers that our principal will be as closely scrutinized as the teaching staff. Auditors have already spent time in the building, generating a long list of changes the district expects Cosmos to make. According to an email from the Cosmos principal these changes include things like “sharper and smarter use of data” to determine regularly-monitored individual teacher goals and “increasing the pace and rigor of instruction” (Cosmos Principal, personal communication, April 16, 2010). It has been an exhausting 10 years.

To me, the most troubling feature of these state and federal designations, reform efforts, rules-changing, and policy making is that no one seems interested in asking the pertinent questions. No one inquires into the purpose of education, no one examines what may be relevant for adolescents in the 21st Century, and never, once, have I heard of an instance when policymakers or district leaders based their decisions on anything the students said.

A pall still hangs over the building like a dark—and permanent—storm cloud. Some of us who have been here a while firmly believe Cosmos is the “kick-me kid” of the district, unsupported, underestimated, and abandoned to flounder on its own most of the time. Nevertheless, while the policy storms continue to swirl around the building and its people, I invite you to take a walk through Cosmos with me.

People and Places of Cosmos High. Cosmos is situated just south of the downtown area and is physically separated from the rest of the city by a major waterway. This geographic reality means the building and its supporting neighborhood are somewhat removed from the rest of the metropolitan area. In fact, “The South Side” has long been home to “separated” groups of people; historically Latino and American

Indian. Today, several first- and second-generation immigrant populations call The South Side home, most of them of Latino, East African, and Southeast Asian origins.

The squat and sprawling building gives the appearance of having just one floor, though it is actually three stories tall. The exterior is dark; brown cement blocks predominate. Near the front entrance there was once a distinguishing 12' tall pillar with Cosmos' name and mascot painted in the school colors. That pillar was annually decorated and desecrated—one year a full-sized bathtub was somehow hoisted to its summit—by the senior class as a lighthearted greeting for everyone's first day back to school. That pillar was recently declared "an eyesore" by someone and torn down; no significant landscape or exterior features remain.

Inside Cosmos, the student body somewhat reflects the neighborhood populace, but because the district employs an "open enrollment" policy, many of the students are bused from neighborhoods throughout the city. To paint a demographic picture, in the 2009-2010 school year, Cosmos students looked like this:

- 45% came from homes where English is the second language or were considered "Limited English Proficient"
- 91% of the students were eligible for free or reduced lunch (usually an indicator the students came from homes at or near the poverty line)
- 24% of the students received special education services or had an Individualized Education Plan (IEP)

- Student ethnicities included: 37% African-American and African Diaspora, 28% Hispanic, 24% Asian-American and Asian Diaspora, 12% European American, 2% American Indian

(Cosmos Principal, personal communication, June 1, 2010.)

Orange, black, and white predominate throughout the halls, floors, furniture, and classrooms; interior colors that prompt me to question whether the décor has changed since 1976, the year the school was last remodeled. Of course, it could be argued that the school colors are also orange and black and the interior paint schemes simply echo that school spirit, but I suspect they are more reflective of the 34 years Cosmos has gone without a makeover.

The following is an excerpt from my teacher's journal dated January 7, 2010, intended to share the feelings and impressions I had one time I needed to make some copies and provided here to give you another glimpse into Cosmos:

Standing at the first floor copy machine, I take in my surroundings. I smell warm paper and dust. This area is "open" in that a huge picture-window-sized cutout looks back out onto the school's main office. I think the copy room's high visibility is a big mistake because this place is truly awful.

A huge recycling bin (one of those 4' blue ones on wheels) blocks a calcified sink. Beyond that is the actual copy machine which works most of the time, I'm happy to report. Directly ahead is a bulletin board that I don't believe has changed once in the 10 years I've been using this room. To the right, there's the cutout window that looks back into the main office, below which is a counter. On that counter dozens of things are stacked, much of it mail to be sorted (which is a mystery because the mailboxes are in a completely different room) and other office flotsam and jetsam that don’t yet have a home. Scattered all about the floor in this room are piles of boxes, a pallet of copy paper, and equipment no one uses anymore (I saw a pile of old typewriters there once).

I got out of there quickly as I found the space to be depressing and ugly and uninviting. I briefly wondered if I should volunteer to "adopt" the room, clean it up, make it prettier and more useful. But reality set in through silent self reprimand, "You don't have the time, don't even start on this." Which may be why the room remains so dismal; perhaps *no one* has the time to improve it.

Somewhere inside me, though, I have the sense that this ugly copy room is like a mirror for this building, reflecting all of us back to ourselves. It is cluttered, outdated, uninviting, and in many ways irrelevant. It serves only to reproduce itself. That depresses me, too.

This is the building within which, for nearly 30 years, the Cosmos D/HH program has been operating. I will introduce you to that program and its students in the next sections.

The Program: Cosmos D/HH

My friend and colleague, Thomas, initiated the Cosmos self-contained D/HH program in the early 1980s. He advocated strongly for this addition to the district's programming because he recognized that the MCDHH students he had been teaching at Lake Elementary (one of the feeder schools for the Cosmos program) were not benefiting from traditional, academically-focused curricula and they would need different supports than those already in place for secondary D/HH students in River City Schools.

It is true there are large numbers of D/HH students for whom traditional programming is appropriate (e.g., Easterbrooks, 1999). It is also true there are equal numbers of D/HH students for whom functional academics and transition skills development[2] are more relevant; MCDHH students typically fall into this latter group (Luckner & Carter, 2001; Reiman, Bullis, & Davis, 1992). The Cosmos D/HH program was intended as an alternative niche for those students who were "lost" or struggling within the system that had thus far frustrated and defeated them.

The River City school district has several secondary buildings but two of them—Cosmos and Park—are large enough to support grades seven through twelve. While general education at the secondary level tends to separate middle- and high-school students, Park and Cosmos are exceptions. Operating under the premise that shared resources and greater course offerings allows students enhanced flexibility and options for development, Cosmos and Park have remained distinctive because of their 7-12 formats (e.g., according to their district website, a neighboring urban school district has no 7-12 buildings). At the time Thomas was starting up his new program, the River City

Schools' D/HH leaders shared the belief that 7-12 programming offers greater opportunities for students. The D/HH leaders at the time also wished to build and maintain a community of D/HH learners similar to those formed in residential schools for the deaf (Baynton, Gannon, & Bergey, 2007), which is probably why both Park and Cosmos were selected as sites for secondary D/HH students in the district. Thomas originally intended to have his students receive the specialized, transition-based instruction he envisioned through the existing Park secondary D/HH program. However, after a year of teaching and working there, it was apparent that Park lacked the services, support, and curricular options his students most needed, so the group was moved and established within the other 7-12 district building, Cosmos; it has been there ever since.

Thomas' new program originally boasted a staff of one licensed D/HH teacher (him) and one educational assistant, a sign language interpreter capable of modifying her signing to accommodate the "low-language" tendencies of MCDHH students. The first Cosmos D/HH staff members were called upon to serve multiple roles as instructors, tutors, advocates, job coaches, interpreters, liaisons, program and service provider coordinators, and IEP managers; these expectations are still in place today. Over the years the numbers of students and, correspondingly, staff in the program have fluctuated with an average of 15 students enrolled annually and an average of seven staff members comprising D/HH teachers, sign language interpreters, and educational assistant paraprofessionals. Support staff and auxiliary service providers such as social workers, language clinicians, and audiologists are not included in this count but regularly work with all Cosmos students.

Like other low-incidence disability special education groups, Cosmos D/HH class sizes were small, usually with five or six students each. Student-staff ratios were rarely more than 5:1. But it was the Cosmos D/HH curriculum that set it apart from the programming at Park as well as most of the typical D/HH programming at that time (Johnson, 2004). Cosmos D/HH was unique because it recognized and addressed the *individual* needs of each student far more deeply than was true when standards and established district curricula dominated teaching practices. Individualized instruction is at the heart of U.S. special education programming (Individuals with Disabilities Education Improvement Act, 2004), but Cosmos D/HH truly embodied that spirit and developed curricular options that were often essential to students' lives. The functional and transition-based programming unique to Cosmos D/HH emphasized applicable—and accessible—skills development opportunities for MCDHH students.

The Cosmos transition and functional programming was structured within state and federal special education guidelines for secondary students (e.g., Repetto, 2003; State Department of Education, 2010). It was also designed around student interests and needs with an eye toward their futures and what would best serve them once they left high school. Transition programming is often multilayered and of longer duration than typical secondary school schedules allow, so students and staff regularly spent three class periods (and sometimes entire days) in these activities; schedule flexibility was imperative. Another important benefit of transition skills development was that, according to graduates of the program who I spoke with for this study, students found them relevant, accessible, authentic, and meaningful. They understood the value of transition lessons and found immediate connections between what they were learning and how these skills mattered for their everyday lives. There used to be five transition areas, but these have recently been consolidated into three new groupings (post-secondary, employment, and independent living). However, the graduates I interviewed all received programming in the original five. Those areas, with examples of how they were highlighted at Cosmos, include:

- *Job skills*: career exploration and awareness; half days on community-based volunteer (non-paid) work sites through a district program and with Cosmos interpreter support; paid OJT (on the job training) support
- *Community participation*: access and regular utilization of public resources such as the library and public transportation; orientation and mobility training was a substantial component of this transition area
- *Recreation/leisure*: exploration of—and exposure to—multiple recreational opportunities including adapted physical education and extracurricular athletics, restaurants and shopping, bowling; hosting biannual gatherings that were regularly attended by program graduates
- *Home living*: meal planning and preparation; personal hygiene and grooming; household chores
- *Post-secondary training*: awareness and exploration of post-secondary options; interest inventories; connections to outside agencies and post-high school programs to establish service continuity

I joined the Cosmos team as a licensed D/HH teacher at the beginning of the 1999-2000 school year. I found I had become part of a well-established, strong, and fully-supported program. At that time Cosmos employed one other licensed D/HH teacher (Thomas) and five sign language interpreters, all of whom had worked closely together for several years. I was instantly welcomed and found that I fit in very well with the ideologies and instructional methods used there. I also adored the kids. Never before had I known the pleasure of working with adolescents who were so candid and straightforward: what you saw was what you got. Overwhelmingly the students were eager to learn, excited about new experiences, and anticipated special events long before they occurred. In direct contrast to most of the teenagers I knew (as well as the adolescent I once was), Cosmos D/HH students were thrilled to attend school every day; most strongly disliked long weekends or holidays and often came to school even when quite ill because being there was always preferred over staying home. I suspect there are multiple reasons for this counter story, for our students' preferences to attend school rather than remain at home, but principal among them might be the lack of meaningful communication at home: I estimate that at least 75% of our D/HH students came from families who did not know or effectively use their child's primary communication mode.

Academically, our students found that they were no longer expected to struggle with confounding and irrelevant English lessons like grammar or punctuation. Instead we emphasized functional language skills like writing personal information, understanding semiotic data like the orientation signs in a store, or writing notes for communicating with hearing individuals who do not sign. Training in language arts at

Cosmos also included enriching students' primary communication mode, usually some form of American Sign Language (ASL) or a sign-English combination; pragmatic and social skills development like conversational turn-taking or age-appropriate conflict resolution; and utilizing technology such as TTYs (teletypewriters) and, later, video phones, email, and text or instant messaging.

The functional mathematics training offered to Cosmos D/HH students highlighted instruction in concepts such as number sense, particularly authentic number sense such as one's age or what it means to have "five" of something; time, such as telling time on both analog and digital clocks or calendrical constructs; and the values of as well as responsible uses for money. As with all content areas, students who could grasp higher mathematical operations were usually mainstreamed in general or cross-categorical special education courses rather than kept in the more restrictive environment of the self-contained D/HH classroom. The difference was that these functional curricular options were now *available* for students who before may not have had the benefit of strongly individualized skills-appropriate instruction.

Cosmos D/HH students graduated almost exclusively with an IEP-driven diploma. That is, rather than expecting students to meet the typical graduation requirements (sufficient number of credits, passing scores on high-stakes standardized tests), students were allowed to count progress toward IEP goals as evidence of learning and sufficient justification for receiving a diploma. In the preface I introduced the individual program alumni who became my research participants. Now I offer you a brief overview of Cosmos D/HH graduates as a whole.

The Participants: Cosmos D/HH Graduates

While the bulk of this writing will be the individual and collective narratives of some Cosmos D/HH graduates, I also want to introduce the participants as a group. The purpose of describing participants' demographic information is because I know of no better way to explain my use of the term "multiply-challenged deaf/hard of hearing" than to let the information speak for itself. As much as I despise labels, no matter how kind or careful I may be as I re-present my graduates, I must sometimes set them apart (from other Cosmos students, from other people with a hearing loss) to explain curricular choices, programming decisions, or the various themes that arose within the graduates' stories.

In many ways, Cosmos D/HH students mirrored their general education peers in that they were at Cosmos from seventh through twelfth grade (our students ranged in age from 12 to 21). Most frequently the kids came from lower-income families and lived in homes where English was not the first language. In fact, a large majority of the students were generation 1.5 or 2 immigrants and most belonged to minoritized racial and/or ethnic groups. I estimate that two-thirds of our students lived in River City (which has an approximate population of 280,000 and is why I consider the area "urban"). The other one-third of the program's students was bused to Cosmos from neighboring districts that could not provide suitable programming for them.

Students' range of hearing losses presented the gamut from profoundly deaf to mild bilateral losses and, correspondingly, their use of amplification (i.e., personal hearing aids) also varied depending on the student and his or her preferences. In most cases, the students might have benefited from amplification but, for their own reasons (e.g., stigma fears, noises unpleasantly amplified into LOUD NOISES), chose not to use it. This was never anything we pushed too heavily with students since we often had to "pick our battles" and amplification was sometimes the least of our concerns.

Most of the Cosmos D/HH students used a manual or signed language; though much of what they produced was technically not American Sign Language (ASL) but rather a "pidgin sign" composed of ASL, English, school, and home signs created by their families. I personally believe that communicative intent and successfully expressing what it is we wish to say are far more important than "correctly" using ASL or, in written language, Standard English. Toward that end, Cosmos D/HH students and staff worked hard to strengthen students' success at conveying their meaning, whatever form that communication took.

Cosmos D/HH students did—and continue to—face many personal challenges because of race, ethnicity, class, hearing, and language differences. This fact of their everyday lives is a reason I included such demographic information in the Participants' Preface. All of my students' differences are "challenges," perhaps, because their personal characteristics lie outside cultural and societal hegemonies and, typically, people do not always know what to think (or how to react) when they meet them. I intend to explore these ideas further in chapter three.

In addition to the multiple differences described above, virtually every Cosmos D/HH student experienced at least one other "educative disability." That is, the students manifested one, and in many cases multiple, additional difference(s) or exceptionalities that qualified them for special education services in U. S. schools. For Cosmos D/HH students, these educative differences were usually cognitive delays, suspected learning disabilities, physical or other health disabilities, and, increasingly, autism spectrum disorders.

Now that I have introduced you to my students as a whole, I will remind you that this writing begins with the introductory stories of the individuals who participated in my study. As you saw then, I interviewed seven men and three women who graduated from the Cosmos D/HH program in the years between 2001-2009. For your reference, and as a brief, overall “quick view” of my participants, I provide their names and individual characteristics in the table that follows.

Table 1. Participant Descriptions

Participant	Gender	Age During Study	Ethnicity	Living Situation	Vocational Situation	Degree of Hearing Loss	Primary Commun-ication Mode	Additional Challenges
Angel	Female	24	East African	With parent	Unemployed	Deaf	Sign language	Delays in language acquisition; no formal schooling until mid-teens; severe economic needs; home language other than English; cultural minoritization; limited communication with others
Cameron	Male	25	African American	Group home	Returning to community-based supported work on a part time basis	Deaf	Sign language	Medical fragility; cognitive delays; cultural minoritization; limited communication with others; limited contact with family members
Choi	Male	27	Lao	With sibling	Unemployed	Deaf	Sign language	Delays in language acquisition; limited communication with others; no formal schooling prior to his early teens; economic disadvantage; cultural minoritization; suspected learning disabilities
Daniel	Male	20	Chicano	With parent	Employed, part time at a fast-food restaurant	Hard of hearing	Spoken English	Cultural minoritization; economic disadvantage; suspected learning disabilities
DJ	Male	29	African American	Group home	Employed, part time community-based supported work	Deaf	Sign language	Cerebral palsy; cognitive delays; cultural minoritization; economic disadvantage; limited communication with others
Ken	Male	22	Hmong American	With parents	Unemployed	Deaf	Sign language	A home language other than English; cultural minoritization; cognitive delays; economic disadvantage; limited communication with others
Scooter	Male	31	European American	With parents	Employed, part time community-based supported work	Deaf	Sign language	Economic disadvantage; cerebral palsy; cognitive delay; limited communication with others
Sky	Female	21	Hmong American	With parents	Employed, part time at a fast-food restaurant	Deaf	Sign language	Cultural minoritization; suspected learning disabilities; limited communication with others
Sweet Girl	Female	29	Cambodian	Group home	Employed, part time community-based supported work	Hard of hearing	Sign language with spoken English	Family issues (including being given away as a ward of the state at age 14); economic disadvantage; delays in language acquisition; no formal school experiences prior to arrival in the U.S.; cultural minoritization; complicated health history and ongoing health needs; cognitive delays
Vue Pao	Male	20	Hmong	With parents	In vocational training; works at community-based sites	Hard of hearing	Spoken English, spoken Hmong	Economic disadvantage; cultural minoritization; cognitive delays

The Researcher: **Me**

I have already been, and will continue to be, quite visible in the work you are now reading. As a critical narrative inquirer I do not believe it is possible to separate myself from my work and, frankly, I do not care to try. I understand that I am in this inquiry completely, from the questions I asked, what I was trying to learn, the stories I share, the language I use to represent the narratives, and how I interpreted what I was told. Everything you read is, in all ways, a result of *me.* To make such a prospect more palatable, I will be as transparent as possible about my motivations, my intentions, and why the stories unfold as they do. Because I will be ever-present in these pages, I thought it best to introduce myself.

In many ways I am like the majority of teachers in the United States (Zumwalt & Craig, 2005); in as many other ways I am not. Like most of my fellow educators and educational researchers, I am a third-generation white middle class American woman. Simultaneously, I have a history of personal circumstances and congenital health differences that set me apart, make my experiences uniquely mine and therefore *unlike* those of my colleagues.

My great-grandparents immigrated to the U.S. from Poland (paternal) and Italy (maternal) near the turn of the twentieth century. Both my parents were born and raised in various parts of the state in which they still live. Both graduated in the early 1960s from River City Schools and neither pursued post-secondary education. My father has worked in retail sales since he was 16 years old and my mother was the stay-at-home kind until I was in my early teens when she went to work as the principal's secretary at my school. I am the oldest of their three children and the only daughter.

I was a "precocious" kid well before I entered school: my mother claims I started talking at nine months of age and I remember spending long hours learning to read before I started kindergarten. I could not be convinced that it was *the school's job* to teach me to read, instead I thought I was supposed to already know how before I got there; interestingly, I didn't care whether or not I could do computation—a trait I still possess. I was born in the summer, so could begin attending school at age five, which I was eager to do. I never went to pre-school or a "head start" program and never attended day care. I loved books, exploration, and learning and never tired of hearing or reading the same stories over and over (more traits I still possess).

One of my observable physical differences has been with me since birth and, because it was all I had known, never hit my childhood radar as anything noteworthy or significant. This condition was identified as rickets (I know: who gets rickets these days besides, maybe, pirates?). Rickets caused me to be a great deal shorter than my siblings and peers, I do not run as quickly as others and I walk with a pronounced, bow-legged, limping gait. However, this difference was never mentioned or discussed in my presence and aside from the foul-tasting medication I took for it every day, I paid no attention to it whatsoever. My untroubled attitude about this "difference" would soon change.

I happily spent kindergarten through fifth grades in two different elementary schools in a River City suburb; this was the 1970s and I don't remember there ever being any kids (or teachers) who were not white. My life, however, negotiated a sharp turn when my family moved twice during the months between the end of my fifth and the beginning of my sixth grade years. I don't really remember those few weeks I spent in my first sixth grade classroom because we were not there very long, I was young, and I don't think they were very pleasant (so I may have blocked them out).

Even less pleasant, albeit *vividly* remembered, was the second school I attended that year. My dad had accepted an opportunity to co-partner and manage a retail store of his own, so we moved out of the middle class suburbs and into a rural part of the state. My parents had soothed the anxious-about-another-move child I was with promises that we would relocate to either a small farm where we could keep a horse (my first choice) or to one of the state's many recreational lakes (also appealing but not as much as the former). Today, with the eyes of an adult who has worked with people living in desperate situations, I am embarrassed by the privilege of both my choices. It is one thing to be afraid of moving, meeting new people, trying to fit in. It is quite another to worry about whether one will eat or have a safe place to sleep. I did not have words for that kind of advantage, nor did I recognize that my life was full of options that, for others, were not so bountiful or fortunate. My parents ended up choosing the lake home and we moved again in October, 1977. I was eleven years old.

Our new house was situated in an area that is zoned for three different school districts and, to my utter regret and dismay, we lived in the zone for a town so small no one has ever heard of it; I will call it Mont Bataille. My brothers and I were bused to school on a route that took an hour one way each day and despite multiple, intensive efforts on my part was never re-routed to create more equitable ride times for the students who shared the route. I still harbor suspicions that my campaigns were ignored because those of us who lived farthest from town were perceived as "rich" and therefore undeserving of additional privileges like fair-minded school bus routing.

My new sixth grade class had 29—that's not a typo, I meant to write *twenty-nine*—students in it. Most of the 28 other kids in the class had known each other since birth and had been attending that small-town, all-white (students and teachers alike) K-12 (the same building housed teachers, students, and classrooms for grades kindergarten through 12) public school their entire lives. More than half of my classmates came from farming families and they held a special disdain for those of us who did not. A *particular* dislike was reserved for anyone they considered "rich;" and because of our house on the lake, "rich" was what I suddenly became (though I'd say my family, particularly in those days, was firmly in the middle class).

One account that later was laughingly, maliciously (I mean, did I *have* to know this story?), and repeatedly retold to me by various classmates is of my coming to that sixth-grade classroom for the first time. Everyone had been alerted to my imminent arrival and one of the popular boys had made frequent comments hoping I'd be "hot" (the appropriateness of this behavior was neither questioned nor challenged from what I can tell). Apparently once I was paraded across the front of the room and introduced to everyone that boy had muttered a dejected, "Aww, man!" There I'd been, dressed in my suburban best (which was nothing like the Levis and t-shirts my new peers favored), trying my hardest to look likable and friend-worthy, and one student, after a single glance, had already decided I was neither. Nor was I "hot." Things went decidedly downhill from there.

The proverbial fish out of water, I languished in my sixth through twelfth grade years, hating it there in Mont Bataille unceasingly. I see now that various attitudes and perceptions about my differences birthed stereotypes that consistently alienated me from my peers. For example, there were attitudes about my physical self: in addition to differences in my physical appearance, rickets also meant "slow and uncoordinated," so I did not benefit from the coolness garnered through athletics. There were also misperceptions about my class status (given where we lived, my family's "wealth" could never be disproved). What interests me most is that the myriad ways I was *the same as* most of my classmates (race/ethnicity, religion, pursuit of academic achievement, heterosexuality) never seemed to balance out the ways that I was not. *Difference always trumped*.

Now, in retrospect, I wish I'd had stronger guides. I wish I had been shown the ways I could simultaneously reappropriate *and* dismantle the stereotypes placed on me (Reyes, 2007). I wish someone had been able to step outside the norms of that school and its culture long enough to embrace those of us who were *always* outside of them. However, to spin these regrets more positively, I also believe that my persistent placement as an outsider in Mont Bataille guided many of the decisions I made—and have been extremely satisfied with—in my adult life. What you are reading is one such product of those decisions.

At least I was able to get away. Recognizing now that my white, middle class status continued/s to afford me multiple privileges, I took advantage of opportunities for mobility and post-secondary education and left the area immediately after high school graduation. I have never looked back. Away from Mont Bataille the world grew to a more representative-of-reality size. I was exposed to points of view and ways of looking at issues that were never embraced—nor were they even *offered*—in Mont Bataille's curriculum. As was true of my elementary school days, my physical differences were once again a non-issue and making/keeping friends was just as easy as it had been in my youth. This fish had found a larger, more diverse pond in which she could thrive.

If you ask my brothers, their stories of growing up in Mont Bataille are very dissimilar from mine; particularly my youngest brother who was only in second grade the year we moved. Because we lived in the same home and therefore shared the same economic class, other explanations must exist for their inherently different—and infinitely more positive—experiences in Mont Bataille. While age and gender may account for some of the variations in our stories, I believe *ability* is the principal explanation for my intensely negative school years. Though the *spoken* message to me was that my perceived economic situation was the reason I was rejected by most of my peers, my able-bodied brothers who shared my identical economic class never paid a price for where we lived or how much money our parents were thought to make. Neither of them have rickets. Neither had any difference that would set them apart from others. Perhaps I cannot isolate singular features and instead must consider the *intersections* of age, gender, and ability characteristics that led to our distinctive experiences in that small, rural context. There is no doubt, however, that those differences were extreme and very, very real. My interests in those intersections are possibly one of the reasons I am a critical narrative inquirer today: I first struggled to make sense of multiplicity when I was quite young. I will continue to try to make sense of it as I wend my way through this dissertation.

I do not mean to sound ungrateful or oblivious to the abundance I enjoy/ed as a child, in my family, and as a white, middle class student in American school systems. I am fully aware of the extraordinary opportunities I have/d and believe whatever obstacles I faced surely helped to shape my personality, choices, and the pathways I would eventually take as I grew up. While I believe we're a product of both our nature *and* our nurturing, I find it curious that although I am the family member who complains most loudly about Mont Bataille, I am also the only one of us with more than a bachelor's degree. I can claim a much less pleasant high school life and a newer, more debilitating difference than rickets ever was (Meniere's disease, which I mentioned at the very start of this chapter and is the cause of my later-acquired hearing loss). Yet I have achieved various personal life goals (volunteering with the Peace Corps, pursuing a PhD) of which I am intensely proud. To my way of thinking, these suggest *something* in me was quite "able" after all. I will look for and highlight similar, ability-focused constructs as I re-present my study participants and their narratives in the pages ahead.

The Study: A Critical Narrative Inquiry

This study of Cosmos D/HH graduates' lived experiences is also about how these individuals taught me alternative ways of understanding ability, schooling, and learning to teach. The work will loosely follow the research methodologies of narrative inquiry (e.g., Clandinin & Connelly, 2000) which I describe in detail in the next chapter. I initiated this narrative inquiry, which I approach from multiple lenses including a social justice perspective, expecting several themes to rise to the surface and become part of the writing; these themes include:

- Myself, my history, my own lived experiences
- My students, their histories, realities, and lived experiences
- Schools and schooling, my teaching practice, the teaching profession, and teacher education
- The stories that are lived in and outside of my classroom
- Hearing loss, special education, ability, exceptionalities
- Urban education, multicultural issues, the intersections of contexts that shape our daily experiences

Many of the themes I anticipated did present themselves quite strongly during my participant interviews, others remained below the surface, unsaid or, perhaps, less important.

The remainder of this writing will include descriptions of my methodological decisions and actions, participant narratives and narrative analyses, and possible interpretations or implications that might be drawn from the narrative data. Through the perspectives and confluences of my personal history, social justice interests and viewpoints, and my own lived experiences I will blend relevant literature, noteworthy discussions, personal anecdotes, and participant narratives throughout the river of ideas this writing is meant to become.

Endnotes

[1] "X," I'm told. The birth years for Generation X vary slightly depending on your source, but Stephey (2008) identifies them as 1965-1980.

[2] Transition in this sense is used to mean the transition from high school to adulthood. Transition is also common language in special education, particularly at the secondary level. For example, assessing skills and creating goals for the transition areas of post-secondary education or training, employment, and independent living is required by state and federal law for all high school students with IEPs (i.e., IDEIA, 2004).

Chapter 2: Telling Our Stories through Narrative Inquiry

I imagine ways to reshape
ever more responsive educative landscapes
for people with disabilities
and for those in relation to them. – Pamela Steeves

Introduction: The Theory and Methodology of Narrative Inquiry

As both a way of knowing (epistemology) and a way of doing (methodology), narrative inquiry appeals to those of us who wish to understand multiplicity and how the intersections of human characteristics, of places, of times, and events influence what we know and do (Clandinin & Connelly, 2000; Connelly & Clandinin, 2006). I am attracted to the ways narrative inquiry gracefully integrates my beliefs about voice, teacher research, story, relationships between researchers and participants, and practical ways of knowing into a single package. Narrative research is also appealing to me because it is quite accessible and makes for engaging, highly-readable texts. So, like many before me (e.g., Bell, 2002; Carter, 1993; Clandinin & Connelly, 2000; Clandinin, Pushor, & Orr, 2007; Elbaz-Luwisch, 1997; Hankins, 2003; Steeves, 2006), I see tremendous potential for narrative in educational research.

In this chapter I will investigate the definitions, key features, and unique aspects of narrative inquiry. I believe these elements make narrative a research paradigm that is more available to a larger group of people, particularly my target audience of pre- and in-service D/HH teachers. My goal for this chapter is to explain my choice of narrative inquiry and how I used it in my study. To do this, I will discuss the theoretical perspectives that frame my work; review the epistemology and methodology of narrative inquiry; identify my research questions and the phenomena I wanted to explore; discuss my data collection and the ways I would approach and analyze that data; and explore some of the ethical questions I encountered along the way.

While I intend to emphasize the features of narrative that were most useful for me, I must also acknowledge that narrative, as a framework for inquiry and research, can be intensely frustrating and nearly impossible to grasp in a straightforward manner; it is best seen from the corner of one's eye. This "peripheral vision" feature of narrative inquiry means it is extremely difficult to write with—or even to write about—and because I have been trained in more positivistic and post-positivistic forms of research, I puzzle over the best ways to portray such a nebulous method of inquiry. Traditional academic text features like linearly laid out chapters, logical progression outlines, or third person omniscient registers do not fit within narrative ideals (nor my own, for that matter), so I must ask readers to set aside familiar approaches to understanding scholarly work in the interest of exploration, innovation, and appreciation for other versions of academic thought. Narrative inquiry demands we rethink the ways information is collected, interpreted, and used (Bell, 2002; Clandinin & Connelly, 2000).

This re-thinking is particularly true for fields of study that, historically, have valued more positivistic definitions of knowledge, though some disciplines like education and medicine now appear more open to the ways narrative inquiries might advance their fields (Carter, 2001; Fenstermacher, 2002; Greenhalgh & Hurwitz, 1999; Schwind, 2003). Of course, this openness is not true of all researchers, including those in my own niche of D/HH education from whom I have found just a single narrative study (i.e., Young & Tattersall, 2005). The failure to embrace narrative research in D/HH education has many possible causes including roots in positivistic educational psychology (e.g., Nolan, 2009) and positions taken by some of its scholars like Kluwin, McAngus, & Feldman (2001) who question the range and analysis capabilities of narrative.

Truthfully, the enigmatic qualities of narrative inquiry flow with *and* against my usual ways of approaching the world. While lived experience and its resultant learning (Elbaz-Luwisch, 2007) are key elements of my own beliefs about knowledge, I am distrustful and intolerant of new age jargon like “wakefulness” as introduced by narrative inquiry pioneers Clandinin and Connelly (2000):

> We characterize narrative inquiry as a kind of fluid inquiry, a kind of inquiry that challenges accepted inquiry and representation assumptions. It is a kind of inquiry that necessitates ongoing reflection, what we have called wakefulness…Others, and perhaps even ourselves, find comfort and a sense of ease within more stable forms of inquiry. We need to be wakeful about what we are doing as narrative inquirers, so we can continue to learn what it means to do narrative inquiry. (p. 184)

Therefore, I have a strong love-hate relationship with narrative inquiry and have spent a great deal of time examining its more unwieldy attributes like the one a colleague astutely described as “contemplating my narrative inquiry navel” (S. Ernst, personal communication, August, 2008). Despite these reservations, I am intuitively convinced that narratives will feel authentic to readers, especially teachers; produce highly-readable, trustworthy, resonant, and engaging texts; and can expand existing definitions of knowledge and educational progress for those of us in the field.

So despite its flaws and their resultant challenges, narrative inquiry remains best-suited to the concepts around which I focus my thinking and research and will best speak to the audiences I most hope to reach. If that means I must spend some time being wakeful about my navel, well, then, so be it.

Ways of Knowing

The Multiple Theories Underlying This Study

This chapter is primarily my interpretation of narrative theory and methodology, but first I explore the range of theories within me that are also ground my study. In the case of narrative knowing, narrative inquiry epistemology has roots in the fields of education, anthropology, and psychology from scholars that include John Dewey, Clifford Geertz, Donald Polkinghorne, and Jerome Bruner (see Clandinin & Connelly, 2000 or Pinnegar & Daynes, 2007 for specific examples). As a narrative inquirer I brought some of these theoretical roots to my research; I explain them in greater detail in the next section.

In addition to narrative ways of knowing I brought other epistemological viewpoints to this study as well. For example, as mentioned earlier, I see most things through a lens I call “multiplicity.” By this I mean that I believe a life, a context, a person or entity, an event, or a system can only be understood on multiple levels and that to flatten or dichotomize something does us a disservice if we expect to know that thing. To me, that’s like saying I “know” a river by holding a cupful of its water in my hand.

As a result, I lean toward social justice theories that espouse multiple lenses and viewpoints. Additionally, such theorists are "unapologetically political" (C. Thul, personal correspondence, February, 2010) and provide forums for the voices of people who are frequently silenced; that is, social justice theorists and researchers maintain that a primary purpose of our work is greater social equity and change (e.g., Kincheloe & McLaren, 2005). I am all of these things, too.

As I hinted in the previous chapter, I also share theoretical viewpoints often emphasized in special education such as the importance of individualizing instruction and the need to view "ability" in far broader terms than is typical of the mainstream. Just as importantly, I believe human beings are complex, multilayered, and "messy" and that we often represent ourselves in contradictory ways (Fine, 1994). In this writing I will attempt to keep that messiness intact and will not simplify or smooth to make anyone feel (or appear) "better." My and my participants' narratives are therefore a fitting vehicle for conveying the human beings we are.

Finally, I strongly agree with Canagarajah (1996) who claims, "Narratives [will] open up possibilities for [marginalized] groups to participate in knowledge construction in the academy" (p. 327). It is my sincere hope that my study participants—marginalized in multiple ways and contexts—will do exactly that and help expand what we understand and do in the field of D/HH education.

To briefly summarize thus far, various ways of knowing and understanding are embedded in this work through several different theoretical lenses. These lenses include narrative; social justice research; special education constructs; acceptance of "messy multiplicity;" and the importance of including historically marginalized individuals in educational research.

Narrative Ways of Knowing

Narrative inquiry as an epistemological framework has three distinctive facets: (a) knowledge as grounded in experience; (b) knowledge as lived within temporal, social, and spatial boundaries; and (c) knowledge as conveyed through story. In this section I further describe and explore these characteristics.

Knowledge As Grounded In Experience. Like other qualitative ways of knowing, a cornerstone of narrative epistemology is that lived experiences are considered the foundations upon which knowledge is formed (Clandinin & Rosiek, 2007). More specifically, narrative inquirers believe there are "multiple ways of knowing and understanding human experience" and that all of those ways are equally valid (Pinnegar & Daynes, 2007, p. 25). Narrative epistemology suggests that we know something because we do it or have lived it, and because we have constructed meaning out of that experience (Bruner, 1994; Polkinghorne, 1988). Clandinin and Rosiek (2007) explain further:

> The narrative inquirer arrives at a very different conception of knowledge than the post-positivist. Whereas post-positivists seek a description of a reality that stands outside human experience, the narrative inquirer seeks a knowledge of human experience that remains within the stream of human lives…narrative inquirers work with an attitude of knowing that other possibilities, interpretations, and ways of explaining things are possible. (pp. 44-46)

Narrative inquiry differs from other forms of qualitative knowing in that narrative researchers believe that the way to *access* experiential knowledge is through told and re-told narratives or story (Clandinin & Connelly, 2000; Pinnegar & Daynes, 2007). While some advocates of narrative inquiry write that people "lead storied lives" (Clandinin & Rosiek, 2007; Connelly & Clandinin, 2006), such assertions trouble me since I do not see all experiences retold through story (agreeing, at least on this point, with Kluwin et al., 2001). Nevertheless, as a teacher who believes in the value of practical knowledge, I do consider lived experience to be a beneficial—though underutilized, particularly in academia—source of insight, understanding, and knowledge. In my case as a special educator working with an extremely low-incidence and rarely-heard student population, I can personally attest to the advantages inherent to listening to my students and the stories of their lives. Indeed, I value listening to *all* people who have historically been "silenced by processes of colonialism, patriarchy, homophobia, and other forms of oppression" (Clandinin & Rosiek, 2007, p. 51). Canagarajah (1996) echoes this sentiment and expands the social justice theory element writing that,

> [Narratives] represent holistically the local knowledge of the communities studied. In opposition to grand theories and global knowledge structures, narratives represent knowledge from the bottom up; in opposition to explicit forms of theorization, they embody implicit forms of reasoning and logic; in opposition to positivistic scholarly discourses which are elitist in their specialized and abstract nature, narratives represent concrete forms of knowledge that are open to further interpretation. (p. 327)

As these scholars suggest, my objective is also to share the experiences of an oft-silenced student group. My hope is that by telling our stories, by listening to—and honoring—alternative ways of knowing (e.g., understanding something because we have experienced it), we can empower those who have been traditionally ignored or marginalized. I believe that sharing our narratives will enrich all of us by expanding accepted definitions of what is and can be known.

Knowledge As Lived Within Temporal, Social, and Spatial Boundaries. Ways of knowing as constructed within time, space, and social interactions are one of the most distinguishing features of narrative inquiry. Simultaneous attention to all three of these "commonplaces" or "three dimensional spaces" (Clandinin & Connelly 2000; Connelly & Clandinin, 2006) occurs in every narrative inquiry. This element of narrative knowing has origins in the work of Polkinghorne (1988) who understood human experience as personal, interactive, and articulated across time through stories. I will briefly describe the commonplaces and the reasons for their importance in constructing narrative knowledge.

- *Temporality*: This element understands that people are dynamic and always growing; while we can only be known or captured at a single moment in time, we also have a past, present, and future (Connelly & Clandinin, 2006) that influence us and our stories as well as how these are understood. When narrative researchers are mindful of the temporality element, they consider people, places, and events to be constantly in process or transition (Clandinin et al., 2007).

- *Sociality:* "Narrative inquirers are concerned with personal conditions and, at the same time, social conditions. By personal conditions we mean the feelings, hopes, desires, aesthetic reactions, and moral dispositions of the person, whether the inquirer or participant" (Connelly & Clandinin, 2006, p. 480). When a narrative inquirer considers the sociality component, s/he is mindful of the myriad social dynamics at play in the research arena. In the case of one of my students this might include that child's degree of hearing loss; personal and family contexts including race, gender, ethnicity, culture, home language, socioeconomic status, sexuality, (dis)ability, age, religious preferences; group of friends; required classes; and school and home communities. The sociality commonplace recognizes, provides a space for, and values the uniqueness and individuality of all persons involved in the inquiry.

- *Place:* While this element obviously refers to the actual physical space in which the inquiry occurs, it can also mean the "sequence of places" (Connelly & Clandinin, 2006, p. 480) that emerge when the other commonplaces of temporality and sociality are explored. So my narrative inquiry may begin in my classroom but could easily take me to past towns (like the one where I grew up), other countries (from which many of my students originated), or venues where we could find ourselves in the conceivable future and the ways those places might impact our narratives.

Knowledge As Conveyed Through Story. This epistemological feature of narrative inquiry holds that stories are the means through which we as human beings interpret and make meaning of our experiences (Connelly & Clandinin, 2006). Narrative inquirers study the stories told to them with the assumption that those narratives are the "fundamental unit[s] that account for human experience" (Pinnegar & Daynes, 2007, p. 4). These interpretations and meaning constructions contribute to our narrative knowledge; without the stories, what they tell could not be known to ourselves nor conveyed to others. Here I will remind you that my participants' narratives are still channeled through me and, therefore, are in danger of misunderstanding or misinterpretation due to my own lenses, experiences, and ways I find myself within the three dimensional spaces of narrative inquiry. For these reasons, I will take great care to explain my decisions and language choices as often as possible as I go about re-presenting the narratives I collected.

One final thought about stories: when considering the types of narratives we use to access what is known or knowable, it is important to recognize that a "story" may be composed in many ways (Clandinin & Connelly, 2000). Hankins (2003) further explains that multiple artifacts might be called "narratives" including works of art, dramatic renderings, interviews, music, writing, as well as the more familiar storytelling. "Narrative," she asserts, "can be more than words, more than story, even more than patterns of speaking" (p.46). So it is that multiple data sources can all be included for their contributions to narrative knowing. I used different forms of narratives throughout the study and this writing, though my primary means for representing narratives are the conversations and interviews I had with my study participants.

Ways of Doing

Overview of the Methodology in Narrative Inquiries

Narrative inquiry as methodology provides the framework within which researchers choose how they will “do” their inquiries. Multiple writers have attempted to define ways of doing narrative inquiry, all, in my opinion, with varying degrees of success. Even the foremost thinkers in narrative methodology offer frustratingly vague explanations like “…narrative inquiry is a process of learning to think narratively, to attend to lives as lived narratively, and to position inquiries within a metaphorical three-dimensional space” (Clandinin & Connelly, 2000, p. 120), although “learning to think narratively” and “attending to lives as lived narratively” are never fully explained. That said, I have gathered key methodological features of narrative inquiries from a variety of writers, especially Clandinin et al. (2007), and offer them below as a way of framing my own research. These key features are: (a) justifying the inquiry; (b) naming the phenomena; (c) describing the ways we study that phenomena; (d) analysis and interpretation of the data; (e) positioning the narrative inquiry within similar research; (f) ethical considerations; and (g) representing the data.

Justifying the Inquiry. Clandinin et al. (2007) suggest that narrative inquirers should be prepared to explain why their study is important; this means we must situate ourselves as researchers into the inquiry, explain the study’s practical value, and consider larger issues and “big ideas” that the study might highlight. In my case, I use the bulk of the first chapter to justify my inquiry. In that chapter I situate the study within district, school, and program contexts and introduce you to my participants and myself as the researcher. I also explain some of my thinking behind the study and the questions that prompted me to begin this work. These, I believe, satisfactorily "justify" my inquiry.

Naming the Phenomena. It is the rare narrative researcher who begins his or her inquiry with established "guiding questions" as is common in other forms of research. Instead we begin by naming what it is we are inquiring into and watching how, over time, our understanding of those phenomena unfolds (Clandinin et al., 2007). In my case, and as I explained earlier, the phenomena that most interested me and centered my study can be expressed through these questions:

- What are the lived experiences and resultant stories of my MCDHH study participants? How can I create a venue for the voices of the formerly voiceless, particularly since this has not yet been done in the field of D/HH education?

- What have these participants, who were once my students, taught me about ways of understanding ability, schools and learning to teach? How can their stories shed light on my practice and, possibly, the practice of pre- and in-service D/HH teachers, particularly those who serve MCDHH students?

- What can our stories contribute to the field of D/HH education? How can we expand our understanding of the work we do with people who have a hearing loss? How would my field change if our stories were told?

These ideas, then, were what I expected my inquiry to be about and in many ways, my predictions came true. At the same time, many other themes I did not foresee also rose to the surface. This new data, that is, the "big ideas" that emerged from my participant narratives, prompted me to deeply consider my graduates' lives as multifaceted and experienced across several different realms. These realms include, and powerfully highlighted, our constructions of ability, schooling, and learning to teach; each of these big ideas will be developed in their own chapters later on.

Describing the Ways I Studied the Phenomena: Participant Interviews. Cosmos D/HH graduates, my former students, were going to be integral to my research from the outset. Their lives as MCDHH individuals are precisely what I wanted to better know and understand, I had worked with many of them for a number of years (some for eight consecutive years), and they were the impetus behind my returning to graduate school in the first place: I had too many unanswered questions and I needed my graduates' help to answer them.

I therefore purposefully selected my study participants. I located Cosmos D/HH graduates through my continued contact with a large number of former students, social Internet spaces like Facebook, and word of mouth or, more accurately, "word of hand" whereby those who had completed their interviews with me encouraged their friends and former classmates to meet with me.

The majority of my time spent with study participants involved unstructured interviews. I did have some planned questions ready (see Appendix A), but more often I honored the ebb and flow of whatever conversation took place naturally and did not necessarily ask the prepared questions. Often our interviews began with participants updating me on their lives, being introduced to people or things important to my graduates (which happened more often when I met participants in their homes), or reestablishing trust and rapport through casual conversation so my participants could feel comfortable and at ease, which was most helpful with graduates I had not seen in a while.

I then explained several important details about why I was there and had asked to meet with them. These details included things like a general description of my study and how it was related to my graduate work; the reasons I wanted to include them in the research; the questions or themes I hoped to explore with them; what I planned to do with their stories; and how they were always free to abandon a question, a topic, or the study altogether if they felt so inclined (see Participant Assent From, Appendix B; both of us got a signed copy before moving forward with the interviews).

I began most of the interviews with the open-ended statement, “So tell me about yourself; who are you?” This yielded as many different responses as I had participants, and not just because of their individual answers to “who are you?” For example, the question proved to be too abstract for some of my graduates. Others seemed almost at a loss about how to describe themselves or what they thought was best to share. Still others regarded the question as downright hilarious: in their minds I knew perfectly well “who they were” and the question was ridiculously silly.[1]

The interviews, which averaged an hour and a half in length, would proceed based on what participants told me, the stories they shared, or what I thought would be a logical follow-up question given whatever they had just said. Sometimes our conversations continued in later emails or other electronic correspondence that was almost always initiated by participants. I also sent a typed summary of each interview to my graduates for “participant checks.” Though I had told participants to expect these, and to solicit help from others if they needed help reading them, the participant checks were successful only some of the time (i.e., only a third of them responded to the “checks” and let me know I had recorded our conversation accurately. The rest of the participants made no remarks about the interview summaries, even if they maintained communication with me afterward). If time had permitted, a follow-up visit with participants to verify my interpretation of our interviews and re-check certain facts would have been extremely helpful. I regret that, due to time and logistical constraints, this was not possible for my study. Follow-up interviews would be terrific to consider for future research, though.

Before beginning the study I had intended to video-record at least some of the interviews. My reasoning for videotaping was to ensure I had accurately reproduced participants’ responses to questions using sign language and to have a visual record of our conversation should I need to revisit it for any reason. When it came time to conduct the interviews, however, I could not bring myself to actually use a video camera. I had experience with ways my students reacted to a camera’s presence in the classroom and did not want to encourage that same silly showiness in my study (though now, in hindsight, I wonder why I thought a research study had to be more restrained than what my classroom can be like). I also admit that I found the idea of using a camera too intrusive, particularly if sensitive subjects were broached. I worried that a camera would be too much of an unnatural interloper or that it would too deeply alter our conversations.

In the end, I couldn’t make myself use the video camera, and deliberately left it at home. I recognize that this decision involved some losses to the overall study. For example, there were probably instances of language, nuance, expression, or other subtle information that I missed in each of the interviews and therefore lost as a result of bypassing the camera. Another downside to not using video was that I, regularly seeking clarification, was more disruptive than I would have liked to be. For example, I often had to stop Choi and ask him to re-state what he said. Then, I sometimes had to ask him to repeat *that* clarification (his sign language can be both confusing and fast). With a camera recording everything, I might not have had to interrupt my participants so often, and especially would not have done so for less critical information like Choi's year of birth. In foregoing the camera I also gave up the chance to revisit my own participation in the interviews. That is, I did not always write my own comments or the things I said to my participants in my field notes, but a record of these may have been helpful when I reviewed them later.

My means for recording the interviews, then, were almost exclusively through typewritten field notes. Because I can type faster than I write, plus can "touch type" and don't need to look at the keyboard while I'm working, I found this to be the best way to keep up with my participants during the interviews. I could watch and fully concentrate on what they were signing and still keep a written, transcript-like record of what was said. I brought a laptop computer to the sessions and typed whatever they told me. This decision to "type and watch" taught me another unexpected, albeit valuable, lesson: my reactions and listening behaviors while I typed were atypical of acceptable sign language exchanges to which my participants sometimes reacted quite strongly! I may be exaggerating when I say that my participants got "freaked out" by this new way of "listening" to them, but the Cosmos D/HH grads did inform me (by inquisitive looks, head tilts, discomfited chuckling) that I was reacting inappropriately compared to normal signed dialogues. I learned to regularly reassure participants that my strange behaviors like wide-eyed watching or excessive head-bobbing (meant to substitute for affirmations or the "uh-huhs" I would normally make with my hands which were occupied in typing) were only because I wanted to accurately record our interviews and not because I no longer knew how to follow conversational conventions.

Describing the Ways I Studied the Phenomena: Other Study Methods. In addition to participant interviews, I kept in touch with Cosmos D/HH graduates through texting, email, and Facebook. As I mentioned before, this contact was almost always initiated by the participants and seemed to serve two purposes: to add something to our earlier interview or, more often, to maintain our reestablished relationship. The latter felt both heartwarming and disconcerting to me. I was, of course, glad to know my former students enjoyed our relationship and wished to stay connected, but I also realized this further blurred what were already very fuzzy boundaries between me, my work as a teacher, and my efforts to behave like a "legitimate" educational researcher.

Then again, it is necessary to point out that, to my study participants at least, there was never a question about who I am; I am their teacher. Surely everyone recognized that I am their *former* teacher, but I was treated as I have always been, a question-answerer, instructor, and advocate. It did not matter how long I described what I was researching, why I was interviewing them, or what I was going to do with their stories, because my identity as "their teacher" was always primary. The fact that I am "at the U" is just a descriptive feature of me like saying I have green eyes or short hair. For my participants, my “researcher” identity did not change who I am in their eyes. In fact, from what they could tell, my role as an academic and researcher never directly impacted them during our shared time in the classroom, and it did not do so as we met for the study even though our interview sessions were, of course, as directly correlated to my researcher self as they were to my teacher self.

From an excerpt about the Cosmos copy room that I provided in chapter one, you know that I kept a teacher’s journal for some months during this study. I intended that journal to be another data source for this research and will use additional entries (or other vignettes from my teacher’s memory) whenever relevant. I must note, however, that half-way through the school year I started to work on what you are now reading. This act effectively replaced much of the journaling I had been doing and I admit my scattered authorial attentions have weakened the journal and its potential usefulness. Still, I believe an occasional journal entry may support parts of this writing and I will include those entries if they help to elucidate our narratives or anything else I’m trying to convey.

One final methodological decision I made is probably quite obvious: I needed to talk to my colleague Thomas. Often. His knowledge of the Cosmos D/HH program, his understanding of the graduates I interviewed, and the sheer number of years he has spent with MCDHH students is unsurpassed in River City Schools and I kept in regular contact with him throughout my data collection. I also had a more formal and structured interview with him once I had completed the conversations with our former students. He was able to answer many of my questions, back up facts the graduates had provided, and offer his point of view on what a participant’s statement might have meant. His support and knowledge has been invaluable both to my teaching practice as well as to this study and I am extremely grateful for his contributions to both.

Data Analysis and Interpretation. One feature of this element in narrative methodology returns us to some of the narrative epistemology detailed above. Much of the data analysis and interpretation in a narrative inquiry involves descriptions, scaffoldings, and explorations of the temporal, social, and spatial commonplaces as well as the ways those were collected or attended to throughout the inquiry (Clandinin et al., 2007). The data, often collected and labeled as "field texts," are expected to stay true to the actual lived experience(s). They must also be reported descriptively and remain within the contexts in which they took place. As I described above, I recorded each of my participant interviews nearly verbatim on a laptop computer. I say "nearly" verbatim because while I am a fast typist, I'm not quite *that* fast and I sometimes had to ask participants to slow down or repeat something I was unsure I'd gotten correctly (or completely). I took care in these notes to describe the setting, the participant, and the ways we had established contact before we met for our interview.

Narrative inquiry "research texts," on the other hand, look more closely at those field texts for whatever meaning or significance they can impart. Research texts are therefore typically a part of the final "representing the data" portion of a narrative inquiry; I explain this methodological element more fully below.

Adding again to the "nebulousness" of narrative inquiry, the process of text analysis and interpretation tends not to be linear (Hankins, 2003) nor should it be considered a "series of steps" (Clandinin & Connelly, 2000, p. 132). Rather, narrative inquiries are considered circular and cyclical, negotiated throughout the analysis, continuously revised and revisited as new data is gathered, and viewed as rich, complex, and representative of multiplicity like the lives depicted within them (Clandinin & Connelly, 2000). This was particularly true for me and this study. Each interview increased the overall research texts in multiple ways, and my loose attitude about scheduling the interviews (which took place over the course of several months) contributed to this issue: I actually made things harder for myself by not holding all of the interviews quickly and having my data all together up front because each new interview did require me to revise and revisit all I had collected up to that point.

Then again, perhaps I simply embodied narrative methodology—or, said differently, I used the methodological approach of a *teacher* more than a typical *researcher*. What I mean is that many researchers, particularly those of us in the socio-historical west, tend to prefer our data be linear, sequential, and proceed from one logical item to the next (Hankins, 2003). However, my research process was more like life in my classroom, which tends to *not* be very linear or logical, especially from an outsider's perspective. Instead, teaching is very much like the cyclical, negotiated, multiplicity-filled reality of narrative research, inquiry, and interpretation. If narrative inquiry is as representative of real life as I think it is, you can anticipate this writing will be full of circuitous prose, meandering narratives, and the unspoken permission to be as descriptive as my details-loving heart wants to be. I therefore was prepared and well-practiced to attempt this kind of research and analysis; it is very aligned with what I already do and who I already am.

Positioning the Narrative Inquiry. This element of narrative methodology is akin to the literature review in other qualitative research (Clandinin et al., 2007). However, some differences remain. For example, while literature reviews traditionally appear as an early chapter in the qualitative dissertation, narrative inquiries position themselves by weaving narrative data and their interpretations with existing literature throughout the entire thesis (Clandinin & Connelly, 2000; Clandinin et al., 2007). This feature of narrative methodology once again reminds us that it is important for narrative inquirers to be mindful of the ways narrative inquiry is similar to, as well as different from, other forms of research. This element is necessary for positioning our inquiry in relation to other forms of research and, more specifically, to explain why narrative is the best way to access and understand what we have discovered (Clandinin et al., 2007). You have already found, and will continue to find, relevant theory and literature threaded throughout this dissertation.

An additional dimension of this element, introduced by Elbaz-Luwisch (1997), argues that narrative research must also be positioned within "the relationship between theory and practice" (p. 77). To me, this means it is possible to consider narratives within multiple contexts, including teaching and learning arenas, even when those contexts are not traditionally recognized as valid within the academy. As a teacher and fledgling researcher this, of course, holds tremendous appeal.

Ethical Considerations. When I conceived of this study and proposed it to my thesis committee and Institutional Review Board, I had several questions regarding ethics and the ways to keep my study participants and their safety and privacy a priority. Most of the narrative inquiry writers I have studied place strong emphasis on the ethics feature of narrative methodology (e.g. Clandinin & Connelly, 2000; Clandinin et al., 2007; Hankins, 2003; Pavlenko, 2002; Steeves, 2006). The fact that most of my former students are vulnerable, special-needs adults makes this issue even larger and more important to me.

In keeping with other details of narrative work, Clandinin and Connelly (2000) write that ethics must be,

> Narrated over the entire narrative inquiry process. They are not dealt with once and for all, as might seem to happen, when ethical review forms are filled out and university approval is sought for our inquiries. Ethical matters shift and change as we move through an inquiry. (p. 170)

Such "narrating ethics over the entire process" is, in my mind, part of the overall writing I have undertaken. I attend to each ethical issue (however mild or thorny) as it arises in this dissertation.

However, some of my original ethical questions remained a constant throughout this study, so I will explain them a bit more now.

How do I ethically, responsibly, respectfully, and confidentially, tell the stories of students with disabilities? Before I began the study I worried a great deal about this question but in actuality it was not really much of a problem at all. I believe I adequately addressed these concerns by nature of my research design. For example, in the case of confidentiality, each participant created his or her own pseudonym. I also changed the names, location identifiers, and distinguishing features of Cosmos, River City Schools, and the state in which we live and work so as to further enhance privacy and confidentiality (some of my data sources are also masked for this same reason, as you will see in Table 2). For varying reasons I decided against video recording (as mentioned above) which had the added and unplanned benefit of greater confidentiality for participants.

As for the questions of “ethically, responsibly, and respectfully,” I relied upon my history of positive interactions with participants, our ability to communicate easily and readily with one another, and our mutual respect and understanding for one another to conduct the interviews. I did not press a point or question if the participant appeared to feel discomfort or was unable to answer a question and I never pushed anyone to participate beyond how they did so voluntarily.

How do I use narrative inquiry with students I have known and worked with for years and not take advantage of the relationships I already have, continue to cultivate, and enjoy tremendously?   This question arose when I read about the researcher-participant relationships typical to narrative inquiries. Additionally, while studying some of the issues encountered by narrative researchers inherent to moving in on specific school spaces (such as those described in Elbaz-Luwisch, 1997), I actually felt like I had the inverse problem: rather than finding it difficult to build and sustain those relationships, I needed to use care to not take advantage of the relationships I already enjoyed. For example, I had to consider what might happen if I decided I had wonderful, important stories to share but, had the students known I would use or re-tell them some time down the road, would have chosen to *not* be a part of the stories as they unfolded. So, in response to this dilemma, I again relied on my research design which means I checked in with participants whenever they were (or might have been) included in the narratives I share in this work.

How will I represent the voices of individuals who often do not have the words or signs for what they wish to express? I thought about this issue when I considered authenticity and trustworthiness, two measures of narrative inquiry quality that I explain in greater detail below. I wondered what would happen if someone challenged a part of my research, asked to see my "evidence" that I had accurately represented my participants. My former students are low-language users of American Sign Language and would not necessarily be correctly understood by, say, an outside sign language user asked to view the videotape. I remember a time that Cameron (you were introduced to him briefly in the preface and will meet him more fully in a chapter five) came up to me once and signed "21." That was it; that was all he said. But I knew that "21" meant "Next week I will turn 21 years old and I am excited about the fact that my birthday is almost here and you will be giving me some special attention then!" For real; that is what he meant. And I know this because I know and understand my students quite well, but an outsider could not necessarily have deciphered what Cameron's "21" truly meant. When I could, I also checked in with Thomas who was able to understand and unravel some of the more confusing stories I got (particularly from Choi). So for my answers to this ethical question, I must ask my readers to trust Thomas' and my history and experience with our students as well as my transparency as I re-tell these stories. You alone will decide whether my work is authentic, trustworthy, and resonates with you;

which are narrative inquiry qualities described in more detail below (I mention them now because I intend to keep them in my sights throughout this writing).

What happens when your research participants are unconcerned about what you do with their stories? This is probably the most vexing of my dilemmas. While checking in with participants to be sure I got their stories right (Connelly & Clandinin, 2006), I realized many other worm cans were opened. One reason was because most of my graduates were not able to read much—or any—of what I wrote. Even if I made the language as simple as possible, many of my participants do not have strong enough English skills to effectively engage in this kind of participant check. I could re-tell the texts back to my students in ways they understand (I did this repeatedly throughout our interviews), but then I must also check for their comprehension (which is another thing I can’t always obtain easily from these individuals who will sometimes claim to understand something and only later reveal they truly had not). I also believe my participants will not necessarily care whether or not I got the story right, though I cannot explain or guess at reasons for this indifference other than the possibility that they, too, rely on the history of our relationship to know that their stories would be in good hands if they gave them to me. I also am lucky that my students appeared to believe and trust that I would take good care of them and what they have to say. This trust is a result of the relationships we have built over time and another reason they may have felt comfortable just telling me their stories and then moving on to the next thing in their day.

I must also note that there is the real concern that any indifference on the part of my participants could simply be the result of an inability to understand abstract concepts like who will read their stories and where this information will go. The responsibility thus becomes mine (as a compassionate, ethical person and as a responsible researcher) to again transparently explain my reasons for including a narrative or anecdote. What I learned about "participant checks" as they relate to ethical research and MCDHH students is that the success (or not) of them will depend on the individual participants, the relationships I have with them, and much time and effort I can expend following up.

Representing the Data. Perhaps the most straightforward of narrative methodological considerations is the way we represent our inquiry. As Clandinin and Connelly (2000) explain, "An inquirer composing a research text looks for the patterns, narrative threads, tensions, and themes either within or across an individual's experience and in the social setting" (p. 132). I spent the bulk of my data analysis doing just this and what I learned I share in the chapters ahead.

Clandinin et al. (2007) nicely describe six different facets of representing the data, they are: (a) crafting the representative research text as narratively as the rest of the work in the inquiry; (b) considering the range of possible text forms that will be most reflective of the narratives you have captured; (c) writing within the commonplaces of time, sociality, and place; (d) remembering our audience; (e) being mindful of the criteria used to judge the work; and (f) being explicit about the ways the study can contribute to the field (pp. 31-33). I interpret each of these elements briefly below:

Crafting the research text narratively means that, like the other steps taken in a narrative inquiry, writing up that work is done the same way. That is, data must be constantly reviewed and revisited (Andrews, 2008) and we must remain mindful of the commonplaces as we re-tell participants' stories because the narratives they provide at one time or place may be different from what they might provide in other contexts or times (Connelly & Clandinin, 2006).

Considering the possible text forms that will be most reflective of the captured narratives harkens back to our earlier discussion of the multiple forms narratives can take (e.g., Hankins, 2003). My reproduction of participant texts will necessarily be two-dimensional, even though their moving, signed narratives are three-dimensional. Perhaps a photograph, drawing, email, or text given to me by one of my participants will best illustrate an idea I am trying to convey or a story they have shared. The point is that the forms the narratives take and the ways I choose to represent them will be as unique and varied as the participants themselves. I cannot tell you how many different versions of the analysis chapters were drafted, nor how many more could conceivably follow the ones I eventually select, but I do know that the writing process has been like peeling an onion. Every time I think I have found a big idea or core thread from the narratives, another layer is revealed. I have done much of the writing, then, by following instinct, poking at larger ideas, and waiting to see what rises to the surface.

Writing within the commonplaces of time, sociality, and place is similar to the "crafting the research text narratively" element described above except that instead of the ways participants and their narratives are influenced by the commonplaces, this feature refers to the ways *the writers* of narrative research are also influenced by those same commonplaces. So this element reminds me that "in a different time, in a different social situation, and for different purposes, a different research text may be written" (Clandinin et al., 2007, p. 32). This element of narrative representation is another reason I make myself so visible throughout this dissertation.

Remembering our audience interests me on multiple levels. My primary purpose is to write a piece of research that will appeal to practicing and future teachers. Learning from my graduates' experiences will directly inform this work. I also write for researchers in the fields of special and D/HH education in order to help them see my students' school and life experiences that could deeply inform the approach taken in special and deaf/hard of hearing education services and research. Finally, I write for myself and my commitment to bridging the gap between schools, communities, educational research, and the individuals intended to be the beneficiaries of our work. It is also relevant to note that, if I am considering my audience while simultaneously working, writing, and thinking narratively, then I must remember that our interests, training, contexts, students, and needs vary widely depending on who we are and when we are reading. Therefore, "our audience" is as multiplicitous and nebulous an entity as narrative inquiry can be.

Being mindful of the criteria that will be used to judge the work allows me to introduce an important element of narrative research that I have hinted about a few times now. While quantitative researchers command their own definitions of what constitutes reliable, valid research, so do qualitative researchers who frequently address reliability and validity through research characteristics like generalizability, triangulation, or "thick descriptions" (Geertz, 1973). Narrative inquirers, however, take other views of these issues and the quality of narrative work is assessed differently. In narrative research, reliability becomes authenticity, validity becomes trustworthiness, and generalizability becomes resonance. This paradigmatic shift is often difficult in the academy because, as Pinnegar and Daynes (2007), explain, “No matter how much they value and embrace narrative knowing, [there are those who] continue to harbor remnants of the positivistic dream of control, prediction, objectivity, and generalizability; letting these glittering stars go is not easy” (p. 15).   Ultimately, it will be up to ourselves, our participants, and our readers to decide if the work appears real and authentic, if we can trust its veracity, and whether or not it resonates within us. I will further explore the issues of authenticity, trustworthiness, and resonance throughout this dissertation because they were at the fore of my thoughts throughout the writing.

Being explicit about the ways the narrative inquiry can contribute to the field is probably best described by Clandinin and Connelly (2000) when they explain,

> The contribution of a narrative inquiry is more often intended to be the creation of a new sense of meaning and significance with respect to the research topic…many narrative studies are judged to be important…for the vicarious testing of life possibilities [offered to] readers of the research. (p. 42)

This element of narrative methodology, again, speaks to whether or not the narrative inquiry research texts presented feel authentic, trustworthy, and resonant but also speaks to one of the larger purposes of research which is to add to the existing knowledge base within a given field; that is, whether the work is “useful.” For the record, the “vicarious testing of life possibilities”—and the chance to use my students’ stories as mirrors for the work you might do with students like mine—is one of my deepest dreams for this writing. If you can draw parallels between our stories and yours, if you can see yourselves in our experiences and determine what you might do or work for you, if you can move forward with the efforts you make on behalf of MCDHH individuals, then I will have achieved my highest hopes for this study.

A Word about Voice

As I have journeyed through doctoral study the issue of voice has grown larger and hairier than ever. As a classroom teacher I never once considered whether or not my voice mattered because it simply flat-out did (or at least I always thought so). My experiences with voice in the academy, however, are nearly the opposite in that I have struggled a great deal to find where my voice might fit.

More important than my own voice, however, are the lives, presence, and voices of my former students for whom I feel a ferocious protection and strong championing based on my many years of teaching and learning experiences with them. Though I struggle to represent these individuals on paper, their spirits and voices are the ones I most care about highlighting. I acknowledge that a two-dimensional representation of a multi-dimensional person through several different moments in time (i.e., the time of our interview, our years in the classroom, the hours I spent writing a chapter) is a difficult undertaking. Still, I insist it is a task worth doing. I could even argue such work is imperative for those of us who wish to effect change in educational practices for MCDHH individuals.

So, despite the incomplete conditions inherent to writing about complex individuals, I still offer you this glimpse into the lived experiences of my participants. I look forward to sharing our stories in the pages ahead so that you might know us better.

Endnotes

[1] DJ, in particular, found the question highly amusing and treated it as an exchange of social pleasantries by answering, "Hello. I am DJ. Who are you?" I was struck by how funny his response was but also realized, for the first time, the strangeness of my question. It was a perfect example of how my students—and graduates—continue to educate me about not taking something I consider "simple" for granted.

[2] I wrote much of this work, and kept my teacher's journal, during the 2009-2010 school year, journaling from approximately August 2009-April 2010. This year also happened to be my first back after a year's sabbatical, which I took to pursue some of my larger doctoral obligations like preliminary exams. And this school year was the first in which I did *not* teach Cosmos MCDHH students full time. Instead, because the numbers for that student population were lower, Thomas was the only teacher who saw them the entire school day. I worked with—and was the IEP manager for—a few of the MCDHH students this year, but my job duties changed significantly. This change in job description was a mixed blessing. On the positive side, greater distance from MCDHH students offered perspectives and clarity regarding some of the work I had done in my former teaching role. A clearer vantage point was also quite beneficial when writing this narrative dissertation. On the negative side, my new teaching job (with, for lack of a better term, "regular, urban D/HH students") was *much* less gratifying for me: I missed the MCDHH students terribly.

Chapter 3: Considering Ability

A core element of the experience of disability is being seen as something you are not, joined with the realization that what you are remains invisible. – C. J. Gill

Disabling Me

Recently I had to make an appointment for a preventive medical appointment I don't much care for, a mammogram. This annual procedure is unpleasant for many reasons, not the least of which is the vulnerability involved in subjecting my poor bosoms to exposure, cold and menacing x-ray machines, and less-than-gentle radiologists. Being the good self-advocate that I am, I took care to use my healthy "compensatory skills" and when I scheduled my appointment (online), made a note that I am hard of hearing. I offered that I was not requesting an interpreter for my appointment (I did not want *another* person in the room!), but that I would need the radiologist to be facing me when they spoke so I would understand their often-complicated directions as they squashed my breasts to and fro. "Just speak clearly and directly to me," I wrote, "and I should be fine."

Not long after my name was called I deeply regretted the decision to reveal my hearing loss and wished I had tried to "pass" (as hearing) instead. Because when the radiologist came to fetch me she held out her arms to stop my progress forward, looked me straight in the eyes, and before a waiting-roomful of people said, "Hel ... lo ... Li ... sa ... How ... are ... you? ... My ... name ... is ... Joan[1] ... I ... will ... be ... work ... ing ... with ... you ... to ... day .... Please ... fol ... low ... me."

These few sentences took more than twice the normal time it would otherwise take to say them. When Joan turned multisyllabic words into single-syllable utterances I knew my self-advocacy had gone awry. I knew, because people do not usually break up their words when they talk to me. I knew because I have watched people speak similarly to anyone they believe might be "foreign." I knew because this has happened to me before. My immediate reactions were shock (at being addressed in this manner) and frustration (it rankles when people misunderstand my needs because *the act of* requesting accommodations makes me vulnerable enough as it is). Mostly, though, I felt diminished.

I quickly decided that the best course of action would be to carry on normally. I responded to Joan in a clear speaking voice (my speech does not reveal my hearing loss) and used a normal rate and cadence in my replies to her. I hoped my modeling the ways I communicate would change Joan's behavior. It ... did ... not.

As the exam—and Joan's misguided treatment of me—went on, my mind raced as I considered my options. What should I do; what would anyone do? I briefly flirted with the idea of mirroring Joan's speech back to her, but discarded the idea as more mean-spirited than I wanted to be. At one point she had me read the clinic's "The Next Steps after Your Visit" document and when I indicated I had finished said, "You've read that already?"

"Yes."

"Well, did you understand it?"

Are you kidding me? Now I was pissed. Tired of feeling vulnerable, annoyed at intolerably long and tedious utterances, and *definitely* sensitive about being thought of as stupid, I tried to regain some of my lost power. I am not proud to report that my first (and unflatteringly arrogant) thought was, "Look, lady, I've got more education than you'll ever dream of." Out loud I replied, "Yes. This is not difficult. Is there some reason I should find it complicated?"

The truth is I was much angrier with myself than I was with this radiologist who clearly had little experience with hearing loss and was, I believe, genuine in her attempts to honor my accommodation request. Yes, I grow weary of always having to be an ambassador for hearing loss. Yes, I am sensitive that not hearing can make me look stupid—like the times I reply inappropriately because I have misheard something—since a large part of my identity has always been wrapped around my intelligence. But this experience was largely my own fault: I allowed Joan's behaviors to silence me. Despite my internal struggling as well as the many years I have endured situations like this one, I did not speak up. I could have changed things in the waiting room with a simple, “Oh, please just speak normally” and not had to carry on for nearly an hour in ways that left me feeling disabled and powerless. The onus for fair and equal treatment was also mine.

Rethinking Ability

In chapter one I told you another of my stories, sharing my memories of growing up in a place where I felt I did not belong. I am convinced that the most significant factors contributing to my otherness were my physical differences precipitated by congenital rickets. This means I have essentially been “different” since the day I was born. My later-acquired hearing loss has compounded these differences and exponentially increased the number of situations in which I struggle to represent my own ability and use—or lose—my voice about who I am and what I can do. I have spent a lifetime trying to make sense of difference and the way constructs of ability are formed. Interactions with strangers like Joan-the-radiologist are not the only times I have struggled with these issues; similar instances have happened with people close to me as well. I still have not forgotten (nor let go of) the way my mother tearfully thanked my husband for “loving me despite my many disabilities;” a statement that both shocked and stunned me because I have never thought of myself as disabled. What, then, do I do with this dissonance between others’ (including *my mother’s*) and my own self-perceptions about who I am? Are all points of view possible? Or true? I tell you all of this because my life and personal experiences have assuredly impacted the ways I consider ability.

I have also tended toward vocational pursuits that allow me to spend more time with my fellow Others, people who tend to live on the fringes of ability and the margins of society. These folks—people with mental illnesses, adolescents adjudicated to a correctional camp, and multiply-challenged deaf/hard of hearing students, for example—have also contributed to my understanding of what it means to be “able.” My Culture and Teaching doctoral program and courses, my examination of relevant literature, my interests in narrative research, and my study participants themselves all highlighted these ideas further and have likewise shaped the ways I regard ability constructs.

This chapter is designed to unwrap some of what I have learned in an ongoing, life-long process of making meaning about ability, particularly within the structures of education and society. I also write this ability theme within the context of hearing loss and the other realities (i.e., ethnicity, religion) shared by my students and the participants for this study. To begin unraveling these overlapping and complicated issues, I offer a brief introduction to education and disability which is often the realm of “special or exceptionalities” scholarship and directly related to my field of D/HH education. I then continue with what my research, my former students, and my own life have shown me about the hearing-dominated hegemonies that permeate our culture and thinking. Finally, I continue to represent the currents of multiplicity that flow through this dissertation as I propose alternative versions of ability, particularly as they are lived and experienced by my research participants.

D/HH Education and (Dis)ability

Overview of Special Education

The field of special or exceptionalities education[2] is vast and has undergone considerable evolution since its inception in the early 1970s (see for example the flow chart on p. 6 in Swanson, 2008). A foundational premise of special education is the belief that all students in the United States, regardless of exceptionality or need, are entitled to a free, appropriate, and public education (Individuals with Disabilities Education Improvement Act, 2004).

Federal legislation thus requires that special education be considered an integral component of public education—as much a part of schools as principals, classrooms, or curriculum might be—rather than as a separate, isolated entity (Council for Exceptional Children, 1997). Special educators, teachers and other service providers like school social workers or audiologists, are trained to "identify children with unusual needs and aid in the effective fulfillment of those needs. Both regular and special school programs play a role in meeting the educational needs of children with exceptionalities" (Council for Exceptional Children, 1997, n.p.).

Swanson (2008) reports that nine percent of school-aged students, roughly six million children overall, receive special education services in U.S. public schools every year. Unfortunately, Swanson does not specify how many of those six million students are deaf or hard of hearing (D/HH) and, instead, lumps such students into an "All Other" category (2008, p. 3). However, River City Schools' state education department reports that D/HH students comprise not quite two percent of all students who receive special education programming in the state (State Department of Education, 2009). Individuals like my study participants who have a hearing loss as well as multiple needs and challenges represent an even smaller slice of the special education pie and tend to comprise less than one percent of those receiving special education services (National Center on Severe and Sensory Disabilities, 2010).

Disability/Exceptionality Categories. There are several educative disability categories, the classifications of which depend on who you ask (i.e., which organization does the defining) or where you are located (i.e., private agencies versus public ones like schools; these also vary from state to state). Below, Table 2 illustrates the different ways disabilities can be categorized and is provided to offer the reader a picture of the depth and breadth of students served by special education in U.S. public schools today. My current and former students have generally been classified as either deaf/hard of hearing, deaf-blind, or severely multiply impaired.

Table 2. Disability Categories Recognized by Two Educational Organizations and by Federal Statute in 2010

Council for Exceptional Children	River City Schools State Department of Education[3]	Individuals with Disabilities Education Improvement Act (IDEIA) of 2004
Autism/Asperger's Syndrome	Autism Spectrum Disorder	Autism
Attention Deficit Hyperactivity Disorder	-	-
Behavior Disorders/Emotional Disturbance	Emotional or Behavioral Disorders	Serious Emotional Disturbance
Blindness –Visual Impairments	Blind-Visually Impaired	Visual Impairments (including blindness)
Communicative Disorders	Deaf/Hard of Hearing Speech or Language Impaired	Hearing Impairments (including deafness) Speech or Language Impairments
Developmental Disabilities	Developmental Delay	-
Gifts and Talents	-	-
Learning Disabilities	Specific Learning Disabilities	Specific Learning Disabilities
Mental Retardation	Developmental Cognitive Disabilities	Mental Retardation
Other Health Impaired	Other Health Disabilities	Other Health Disabilities
Physical Disabilities	Physically Impaired	Orthopedic Impairments
Traumatic Brain Injury	Traumatic Brain Injury	Traumatic Brain Injury
Twice Exceptional	Deaf-Blind Severely Multiply Impaired	-

I include this descriptive and numerical data because I believe it has important ramifications for students like mine. For one thing, disability categories that are founded on deficit models and generalizations about the characteristics of individuals within those categories can lead to false assumptions and understandings about those individuals and their needs (Johnson & McIntosh, 2009). Also, the fact of low numbers implies such students may be insufficiently represented in the research and educational practices intended to serve exceptional children. So students like mine are at risk for both mis- and under-representation. In my own efforts to uncover relevant academic writing and research about MCDHH students I have found such children might be recognized as a burgeoning population of students with unique needs (i.e., Luckner & Carter, 2001;

Spencer & Marschark, 2010) or as typically-underserved (i.e., Easterbrooks, 1999; Johnson, 2004), but are rarely the focus of—or participants in—educational research.

Including D/HH Students in Special Education Conversations

There are arguments for and against including D/HH learners in special education categories. On the "for" side of the debate, scholars such as Easterbrooks (1999) point out that the fact of multiple service providers (i.e., audiologists, speech/language clinicians, social workers) common to D/HH education is reason enough to include D/HH learners in conversations about special education. There is also the fact that most D/HH teachers receive specialized training that is relevant to an extremely low-incidence yet highly-heterogeneous student population (Spencer & Marschark, 2010; York-Barr, Sommerness, Duke, & Ghere, 2005) and, for many, this specialization warrants D/HH inclusion in special education. There are several more researchers who consider D/HH and special education as a synonymous "given;" the mutual grouping appears to almost be taken for granted. This automatic assumption may in part be due to federal legislation (i.e., Individuals with Disabilities Education Improvement Act, 2004; NCLB, 2003) that has already done the defining and classifying for us. Therefore, many researchers in D/HH education (e.g., Johnson, 2004; Luckner, Muir, Howell, Sebald, & Young, 2005; Meadow-Orlans, 2001) accept that special education is part and parcel of this field; they suggest we must do our work *within* existing special education structures.

Arguments against considering D/HH as appropriately-situated within special education are slowly gaining a foothold in the field (e.g., Johnson & McIntosh, 2009; Komesaroff, 2008) and often use socio-cultural (versus physiological or deficit) models when arguing against placing D/HH learners into disability categories. Johnson and McIntosh (2009) suggest that hearing loss is sometimes identified separately from other disability categories to allow for “the possibility of alternative understandings of Deafness as a cultural and linguistic minority rather than as a disability” (p. 74). Padden and Humphries (1988) also represent this socio-cultural viewpoint, albeit somewhat differently, when they write:

> The traditional way of writing about Deaf people is to focus on the fact of their condition—that they do not hear—and to interpret all other aspects of their lives as consequences of this fact. Our goal in this book is to write about Deaf people in a new and different way. In contrast to the long history of writings that treat them as medical cases, or as people with “disabilities,” who “compensate” for their deafness by using sign language, we want to portray the lives they live, their art and performances, their everyday talk, their shared myths, and the lessons they teach one another. We have always felt that the attention given to the physical condition of not hearing has obscured far more interesting facets of Deaf peoples’ lives. (p. 1)

Note that both citations from socio-cultural writers utilize the capital-D Deaf literary construct which is often used to denote identification with Deaf Culture. Such individuals usually call ASL their first language and so consider themselves members of a cultural and linguistic minority. When deaf is kept lowercase, it refers to anyone with a hearing loss profound enough to prevent access to spoken language or, said another way, the absence of hearing in an audiological sense (Senghas & Monaghan, 2002).

I personally fall in the middle of the continuum on this debate. I agree children with a hearing loss are highly heterogeneous, thus requiring individualized instruction on a per-student basis, which is a hallmark of special education. Likewise, I agree D/HH teachers receive more "specialized," disability-specific training which sets us apart from the preparation and professional development other educators receive. Still, I do not necessarily consider "the condition of not hearing" as inherently disabling, though it can be depending on the situation, as was true in "the mammogram story" I shared at the start of this chapter. I also have trouble understanding the benefits that may be gained by fighting for "cultural and linguistic minority" rights because not all people with a hearing loss identify as members of the capital-D Deaf community and are therefore not included in these civil rights conversations.

Thus, to consider the ability question within the context of my study, I returned to the narratives I collected. What did my participants tell me about "being able?" Do the for and against debates about special education and hearing loss even matter? Did my graduates recount experiences like mine in which they have "been disabled" by others? If so, how did they understand those experiences and how did they retell them to me?

I was surprised to discover that not one of my former students even *mentioned* being deaf or hard of hearing until I asked them about it. None of my participants included their hearing loss as a part of themselves, their experiences, or their identity, and none recognized that the services they received at Cosmos were because of the fact they do not have typical hearing. They were all, as Daniel expressed, "just themselves." Perhaps highlighting the notion that school is about much more than academic learning (i.e., Cerney, 2007, who frequently refers to the socio-emotional development inherent to schooling), my study participants were not interested in speculating whether or not they are "disabled." They did not share memories of times they felt the need to advocate for themselves, and their stories did not include questions about their abilities. Rather, they identified much more frequently with other, more dominant discourses that contribute to their notions of who they are. They told me about their work, their living situations, their families, or what their lives were like before and after immigrating to the U.S. It was the *absence* of disability-focused narratives and the refusal to frame themselves within ability/disability constructs that caught my attention and holds my interest now.

Among the many disassociations from disability that I encountered in my interviews, I found the distance between my participants and the themes that are regularly emphasized in D/HH education and research to be particularly provocative. My former students were unconcerned with "evidence-based practices," whether or not they would have benefited from a cochlear implant, perceptions about their language achievement, or whether D/HH students belong in special education categories. My study participants forced me to consider that our time in education and research might be better spent elsewhere. That is, there may be other themes that matter more to the students we serve and that merit more of our attention than the areas upon which our research and practice energies have traditionally been placed. As a result of my studies, I argue that understanding larger issues—such as the way hearing typically pervades our culture and society in ways that disable individuals who do not hear in the same way—deserve more of our attention than, say, quibbling over whether or not D/HH learners should be taught in bilingual[4] classrooms.

Thus, to explore these ideas further, I had to step away from the bulk of D/HH education scholarship and research to instead explore memoirs, narratives, and my own research data. To understand “ability” as experienced by D/HH individuals I needed to read or be told stories from the people who are frequently considered *not* able for one reason or another. I share what I discovered in the sections below.

Stories about Hearing-Centric Hegemonies

I grew up hearing and live in a culture and society for whom typical hearing is also the norm. While I work in a field that serves students with a hearing loss, this field is still primarily staffed, administrated, and researched by professionals who also have typical hearing (Hoffmeister, 1996). Now, after twenty-some years of living with my own hearing loss including more than a decade of working in D/HH education, I realize that I have still managed to maintain a hearing-dominated viewpoint and lifestyle. For example, the majority of my friends and family, my colleagues, and my spouse all hear typically. Additionally, my recreational choices, vocation, and avocational pursuits have, for the most part, not changed much from the days when I, too, was hearing.

Slowly, as I sharpened my study of D/HH education within the larger constructs of culture and education, something about this hearing dominance began to trouble me. First, I had to recognize the existence of hearing-centrism, a term I use to mean the ways hearing-dominated points of view permeate nearly everything in our culture and society. Are hearing-centric hegemonies at play in my field and the larger arenas of education and learning? Just as importantly, does hearing-centrism matter? Does a hearing-dominated society impact the lives of my students or other MCDHH people?

Exploring Hearing-Centrism. These questions (immediately above) are important to me because I believe that the contexts and circumstances surrounding my participants' narratives need to be understood as directly shaping the ways we understand and tell our stories as well as what we understand those stories to mean. For example, my experiences as a later-deafened adult will be much different from the stories that people who are born with a hearing loss might tell. Also, within those groups of D/HH people, the infinite combination of qualities that shape who we are and the kinds of lives we will lead generates a rich array of narratives.

Baynton, et al. (2007) beautifully illustrate this point, and the possible repercussions of ignoring hearing-centric context, when they explain:

> Hearing people often fail to make the distinction between those who grow up deaf and see themselves as part of a proud and close-knit minority, and those who are traumatized by losing their hearing in adulthood. When they imagine what it might be like to be deaf, their first thoughts are often about how much they would miss music…the theme of deafness as the loss of something essential to the experience of joy in life has been repeated many times in literature and mass media over the years. Often these portrayals have had a greater impact on public perceptions of deafness than anything that deaf people may say about their actual lives and experiences. (pp. 110-111)

This message is an important reminder that people in the majority, those who hear typically, tend to impose hearing-based values and world views on people with a hearing loss. Much like the dominant members of any paradigm, hearing people usually see the world in “a hearing way” and must be taught other, equally-rich and valuable ways of being (Komesaroff, 2008); that is to say, we must offer alternative narratives. I offer several of these in the next sections.

Alternative Narratives

“Being Hearing Is Harder.”

Nearly all of my former students offered alternative worldviews from those of the hearing majority. Before I share these, though, please allow me to introduce their alternative narratives by opening with a popular and widely-distributed story in Deaf culture from one of its members, Dr. Sam Supalla, as told by Baynton et al. (2007):

> There was a little girl who lived next door, a neighbor, and she didn’t sign. I used gestures to communicate with her. One day I was in her house and saw her talking with her mother by using their lips. It was so different; they didn’t sign at all. I ran home and asked my mother what was happening there and she said that they are hearing; it was called being hearing. So I asked, “If they’re hearing, what are we?”
>
> My mother said, “You’re Deaf, I’m Deaf, your father is Deaf; your brothers are Deaf.”
>
> I asked, “Well, if we’re Deaf, is this girl the only hearing one?”
>
> “No,” my mother explained, “most people are like her.” (p. 3)

In my reading I found that variations of Supalla's story were very common for deaf children raised in deaf families. In deaf-centered contexts, hearing people were the different ones, the "others" that mostly existed on the periphery of their attention and, when acknowledged at all, were considered "disabled" because of their inability to communicate in sign (Padden & Humphries, 1988).

My study participants echoed this sentiment many times, especially when I asked the question, "Do you think it is easier or harder for you because you are D/HH?" I expected them to reflect my own experiences: that living with a hearing loss makes life more challenging in a hearing-dominated world. Overwhelmingly, though, my former students surprised me by answering quite differently:

> Easier. My life is easier because I am deaf. I became an actor, meaning that I learned to express myself really well, very clearly, using my facial expressions and body language and stuff like that. (Scooter)

> Being hearing is harder. Since I can't hear when someone is talking, I learned to write, to exchange notes, that makes it easier to clarify something and [communication] is okay. It's easier for deaf and hard of hearing people because we can sign, too. Hearing people can't. We can do both [sign and communicate in English]. (Ken)

> I don't think the hearing loss was ever a big deal. My mom wanted me to go to school and learn English and sign language. I tried! I tried! But [learning sign] didn't go so well. Still, my mom was really proud of me when C. (a current Cosmos student) and Ken came to my house and were signing to me. I could sign to them, too, and my mom was proud of me that I could learn the skills and talk to them. They (C. and Ken) were proud of me, too; they told me I knew "just a little bit" but it was enough! (Vue Pao)

As you can see, most of my graduates did not repeat dominant discourses about hearing loss. Instead, they were certain that a hearing loss need not necessarily mean a more difficult or challenging life. Rather, their hearing losses forced them to develop rich and useful means of communicating that they would not have learned if they had typical hearing. My graduates, then, reminded me that "ability" can be perceived and understood in multiple ways.

When Being Deaf Means Belonging. A second alternative narrative comes to us from Leah Hager Cohen (1994), a hearing journalist who lived the first seven years of her life at New York's Lexington School for the Deaf where her father was the principal:

> I played at signing the way other children play dress-up; part of trying on possibilities, practicing for the future, it was laden with excitement and anticipation, even aspiration. I wanted to grow up and be deaf, be a Lexington student, with all the accouterments: hearing aids, speech lessons, fast and clever hands…but I was not the same. One afternoon, while playing with my classmates

> outside, I sought to remedy my most blatant difference. I selected two pebbles—urban pebbles, rough bits of dark gravel—from the ground and set them in the shallow cups of cartilage above my earlobes. When the teacher spied my improvised hearing aids, I was thoroughly scolded. "Never put *anything* smaller than your elbow in your ear!" was her mystifying admonishment. Puzzling over this helped deflect some of my embarrassment and hurt, but it did nothing to help me fit in with others. I sorely envied my classmates their speech lessons. Whenever I had occasion to peek into one of the closet-size speech rooms along the hall, I drank in the scenery, the exotic paraphernalia—mirrors and flash cards, balloons and balls feathers and tongue depressors—with a lustful, wondering eye. I didn't know then that many deaf children loathe speech lessons, experience them as something designed for humiliation and failure. (pp. 10-11)

Unlike the hearing-centric point of view, in this story Cohen holds that *deafness* is desirable. Her difference—that she can hear—is something she wishes to downplay or overcome. Cohen's story illustrates her wish to fit in and be like everyone else, but in her situation, fitting in meant *not* hearing.

Another interesting variation in the stories about fitting in comes from Swiller (2007), who explains that it was sometimes possible, given the right context and people, to function as a hearing person would. This, he acknowledges, "made day-to-day life a hell of a lot easier" (p. 185). In the African village where he worked as a Peace Corps Volunteer, everyone spoke loudly and clearly and their efforts to include him helped Swiller to feel as though he belonged:

> For the first time in my life, deafness was gone. Or not gone—I still couldn't tell whether that noise was a man calling or a dog barking, or if this one was a child crying or a bird song and I still, of course, missed all conversation that wasn't said directly to me—I mean that for the first time deafness did not close off a single possibility. That was a lovely feeling. (p. 95)

Even though accommodations were required (i.e., people speaking directly to him), his hearing loss did not create issues of belonging for Swiller. What I find interesting, though, is that he needed to "hear" to "belong" at all. For Swiller, performing more like the hearing majority was what he needed to feel included.

Most of my study participants also reflected the wish to belong, but none of them said belonging had anything to do with hearing. Rather, graduates of the Cosmos D/HH program reported feeling far more occupied with being a part of Cosmos' culture and participating in school activities like extra-curricular or mainstream programming that everyone else enjoyed:

> I loved showing up (at school) every day, waking up, coming to the building. I also loved watching the games, the sports. (Choi)

> I enjoyed coming to classes here at Cosmos. I liked the mainstream classes. I learned. I took ceramics, drawing, physical education, JROTC, keyboarding. (Ken)

Several of my current students also feel strongly about belonging and the wish to interact with everyone at Cosmos, but do sometimes find their hearing loss to be a barrier to belonging. One exasperated student recently exclaimed, "The whole world is hearing, but I want to be part of the whole world, too!"

The Whole World Is *Not* Hearing. One response to my student's frustration might be to encourage conversations about hearing-centric paradigms and ways we-in-the-minority might effect change. Though it can be tiring to constantly represent people with a hearing loss, we might reclaim lost power and reestablish our places in this world through the use of our voices, sharing our experiences, and educating others.

As I mentioned before, none of my study participants identified themselves as having a hearing loss until I brought it up. Equally-importantly, none of them recognized any of their other multiple challenges (i.e., co-existing disabilities, socioeconomic realities) as central to who they are. In their minds, such features fell well below their radars and were not worthy of a mention until I inquired about them. Once I did, the responses were more similar to this one from Daniel, who is hard of hearing:

> I was always just me. My hearing loss is not a big deal. I can hear well. Sometimes I don't even tell people [I have a hearing loss]. Lots of times people tell me, "Oh, we didn't know!" I get that a lot. Sure, it might be harder for me if people speak quietly, or if they talk with their mouths blocked or their backs turned. If I was sitting in the back of the room, that was hard; but I didn't know why until my teacher explained it to me. I just remember thinking, "But I am normal. I don't have any problems."

Similarly, Angel did not find her deafness to be a significant barrier to her getting along in the world or discovering where she might belong, nor did it cause her to question her abilities. While Angel did experience challenges related to her Muslim faith, these situations did not take away her power, presence, or voice:

> Some of the hearing kids were mean, but sometimes the hard of hearing and deaf kids were, too. Like, T. (a former student I did not interview for this study). He sometimes called me "weird," said my clothes (the hijab and other items typical of Islamic women's attire) were weird. I'd always say, "Stop, stop!" but he always asked me why I dress like I do, why I won't wear pants. I explained, I told him I'm from a different country, my religion is different, but he always bothered me. He tried to talk to me at the party (the holiday party that took place just before our interview), but I remembered his meanness and I ignored him.

In addition to my participants' stories, another reminder that the world is not always hearing is an historical one. Baynton et al. (2007) tell a story that helps to illuminate the ways society and culture construct the definitions of difference and how adjustments to our expectations for communication can reap large benefits:

> Deaf people live in every community. In most times and places their numbers are small, but exceptions appear from time to time. One such exception took place on Martha's Vineyard from the seventeenth to the early twentieth centuries. Because

> of an unusually high rate of inherited deafness on the island during that period, many people were bilingual in English and sign language. Consequently, deafness appears to have had little effect on social relations. In the general U.S. population, fewer than 1 in 5,000 children were born deaf at that time (many more became deaf from illness), but on Martha's Vineyard the number was closer to 1 in 150, and on parts of the island it was as high as 1 in 25. As a result, many hearing islanders were able to switch back and forth from spoken English to sign language depending upon who was present, and there seems to have been no difference between the social and economic lives of hearing and deaf people. They intermarried regularly, did the same sorts of work, earned the same incomes, and participated in the daily life of their communities on an apparently equal basis. (p. 8)

The stories from Martha's Vineyard demonstrate the impact of context on definitions and the ways "handicaps" are socially constructed. Those who did not hear were just as useful to island society as those who did because efforts were made to be inclusive, particularly with regard to communication. One layer of "ability," then, requires a similar brand of inclusiveness. This means a willingness to both learn about the needs of others and then adjust our behaviors accordingly, which is something I wish Joan-the-radiologist had known and been able to do. I also forgot my own role in this endeavor.

Multiple Versions of Ability

If we wish to integrate alternative narratives and then redefine how we view (dis)ability, we might begin by considering multiple versions of the construct. My study participants provided me with different ways they understand themselves to be quite "able," even if these are not readily recognized by a hearing- and able-dominated society. For instance, Scooter gave me an ebullient vision for himself and his future that illustrates different ways to imagine ability:

> I want to find a beautiful girl, start as friends. Later maybe we'll go out on dates to the movies or a restaurant. I also want to save money for a house, like if me and the pretty girl get married, we'll need to work, save, buy a house so we have a good place to live. Also, me and the missus [wife] might want to discuss whether or not we want kids. I don't think I want children, but maybe; we'd have to talk about it first.

Those of us who know Scooter well may not agree that marriage and children are likely for his future. He does not seem independent, skilled, or savvy enough to manage life in ways that are expected of other 31 year olds or people who wish to marry and raise a family. Still, for Scooter, these are firmly within bounds and part of a future he expects to pursue. He treats his dreams as confidently as you or I treat our own.

Many of my other graduates also did not hesitate to proclaim their places in the world; they know they belong and they have plenty of ideas as to where. Sweet Girl provides a strong example of this when she shares:

> My dreams are to live on my own, independently. I also dream of learning how to drive, having my own independent means for transportation. I also want to work independently, without a job

> coach. And I still want to attend college and get into a beauty school program.

To achieve these dreams, Sweet Girl would have to overcome some significant barriers including physical differences that would make handling a car quite challenging and English skills that may not be sufficient to manage "college" or beauty school admission. So when I asked her how she plans to achieve her goals she was the first—and only—of my participants to refer to exceptionalities when she replied:

> I've got support and advocates. I also attend special trainings to better understand the rights of people with disabilities. One of the things I learned at those trainings is that it is my right, when I don't understand something, to have it explained to me in an organized, orderly way. They must answer all of my wh- questions like where, when, who so that everything is clear.

Sweet Girl, then, relies on her civil rights as well as her rights as an individual with exceptionalities to accomplish her goals. In her mind, she is just as "able" as anyone else but that certain adaptations are needed to achieve them. Those basic accommodations, such as "explaining things in an organized, orderly way," Sweet Girl believes will even the playing field and allow her to be just as "able" as anyone else. This sentiment reminds me of the way things used to be on Martha's Vineyard when people switched between spoken and signed language to accommodate their listener; the communication mode employed was naturally dependent on the situation and the people involved. So, rather than pounding square pegs to fit into round holes, a subtle shift to a square hole may be all we need.

Thus, my exchange with Sweet Girl was one rich example of the ways my research participants got me to consider “ability” and alternative definitions of how that construct might be produced. It also was the impetus behind my search for the ways my current and former students were showing me how able they are, how well they can independently navigate through a hearing- and ability-dominated society. Once I started looking for them, I realized they exhibited dozens of ways they so capably maneuver through their lives. For example, one of them (who I did not interview for this study) recently posted this message on her Facebook wall:

> I am feel sick cuz my brain just start headache worst....

When I saw this sentence, I was so charmed I laughed out loud. I was delighted by the image my graduate invoked, but, even more I was impressed with her skill in communicating exactly what was happening for her at that moment. No, the English is not perfect; the grammar, punctuation, and idiom are all incorrect. Yet she was independently able to access the social media tool she wanted to use, locate the correct space in which to put her message, type and send the text, and express a clear state of being that left no doubts about how she felt. If only all of us were so skilled at expressing ourselves and our inner states of being, be it on Facebook or wherever!

I am heartened—and emboldened—both by history and by the ways my study participants live and talk about difference. I believe that if we can define disabilities by cultural perspectives and paradigms, then we can also redefine them (or eliminate them altogether). Such redefinitions, of course, will require adaptations and a willingness to change, particularly on the part of the majority (Groce, 1985). Because of my own experiences as well as my reading and research, this is not something I am certain the dominant group is willing to do. Therefore, my responsibility is clear: I must say something, and I must encourage change. If I ignore or gloss over instances of injustice and discomfort like the one I had with Radiologist Joan, they will continue. Like it or not, I must act as that “ambassador for hearing loss” because doing so might change the ways marginalized groups are perceived, constructed, or silenced.

Endnotes

[1] I don’t really know or remember what her name was as she caught me so off-guard by talking to me as though I were a toddler I did not pay close attention to what she was actually saying. Still, in keeping with the rest of this work, “Joan” is probably a pseudonym.

[2] A word about terminology: as part of special education’s evolution, names, categories, and disability labels have been repeatedly revised to better represent the children who live with various educative differences. For example, the current category “deaf/hard of hearing” has had several other names including “hearing impairments,” “hearing handicaps,” and “hearing disorders” (Hoffmeister, 1996). As noted in Table 2, the Council for Exceptional Children and IDEIA 2004 do not even have a category for D/HH and place such children within the “communication disorders” grouping. Verbiage confusion is also evident in my interchangeable use of terms like “special” and “exceptional.” Because they are most familiar to me and best reflect my experiences as a teacher in the field, I tend to use “special education” and “disability” terms more frequently than words like “exceptionalities” or “differences.” However, it is important to make a careful distinction: while this is the language I automatically use because of my professional experiences, contexts, and history, use of these terms is not necessarily reflective of my attitudes or beliefs about difference.

[3] This data was collected from River City Schools’ state department of education website in the year I wrote this dissertation (2010). However, I have omitted the citation and reference URL for this information. There are very few programs and school districts who serve students like mine, so revealing the state information would make it quite easy to identify Cosmos and River City Schools. Therefore, in order to protect the privacy and anonymity of my participants, I will not provide the true source citation for this data.

[4] In the case of U. S. deaf learners the languages in question are usually English and American Sign Language.

Chapter 4: Schooling

The emancipatory possibilities embodied in relational narrative inquiry
drew [narrative inquirers] to explore the stories of those who live on the edges,
almost invisible in the social/cultural/institutional plot lines that shape us all.
– D. Jean Clandinin and Heather Raymond

Introduction: Schooling at Cosmos

When I began this study, one of the questions I wondered was how my students and, especially, my study participants taught me new ways of understanding schooling. I wondered how their stories would shed light on my practice and, possibly, the practice of pre- and in-service D/HH teachers, especially those of us who serve MCDHH students. This chapter explores some of their answers to those questions.

I was gratified to discover that almost everyone I talked to reminisced about their time at Cosmos quite fondly (the exception was Cameron; I will explain this further in the next chapter). Many of my graduates reminded me of different experiences we had shared that I had long forgotten or had never realized were so meaningful to students; we laughed frequently during the interviews, enjoying the walks down memory lane. Through participants' narratives I discovered that the Cosmos D/HH programming impacted them in varying ways, but the frequency with which a few key program elements were mentioned caught my attention. As the interviews went on, I was increasingly interested to observe that the same themes surfaced again and again. I realized these elements were uniformly powerful for my graduates. The strongest and most regularly-noted school and curricular components were transition training, extra-curricular opportunities, and special events. I will explain them more fully in the next few sections.

Transition: Jobs and Work

As I described in chapter one, transition training at Cosmos follows state and federal guidelines for special education (Individuals with Disabilities Education Improvement Act, 2004). The purpose of transition training is to increase life skills (e.g., work and career exploration, mobility, independent living tasks) for students with exceptionalities. The graduates I interviewed were particularly positive about the transition skills opportunities they encountered in the Cosmos D/HH program.

I personally believe that transition training is a highlight of Cosmos D/HH programming and sets us apart from other school-based programs for students with a hearing loss. The multiple challenges that most of our students face necessitate authentic, experiential, real-world opportunities to develop the skills these students would need as they approached adulthood. Transition training was always at the center of our curriculum and program so, perhaps logically, was one of the areas my study participants recalled with the most energy and praise.

Work Experiences Training and Career Exploration. A large number of my former students recalled the many work opportunities they had at Cosmos, most of them through a community-based job skills development program operated by River City Schools. This program, which I will call JOBS, provides students with a variety of work experiences including office and clerical, custodial, retail, warehouse, child care, elderly care, and food preparation in public locales such as retail grocery stores, nursing homes, private businesses, or other schools and administrative buildings in the River City school district. The JOBS program also provides work coaches who supervise students in their daily duties and offer student-specific work skills instruction like staying on task, anticipating what needs to be done next, or working productively when the supervisor is not present.

Most Cosmos D/HH students, particularly those who use ASL to communicate, were also provided with a sign language interpreter on these JOBS experiences; often the interpreter was the primary job coach at the work site and functioned as a communication liaison as well as work supervisor. The majority of my study participants spoke highly of their JOBS opportunities and the interpreters who worked with them at their sites, DJ's story mirrors many of their narratives when he recounts:

> I remember going to work where I cleaned. I also worked in the kitchens at the university; I did that job with my good friend who moved to Arizona. Then I worked at the recycling center which I really loved; I got to do a lot of physical work that was good. I also worked in the office for an adoption agency but that wasn't really my favorite; I'd rather be moving around.

Jobs and Work after Cosmos. Just as they spoke highly of their work experiences while in school, my graduates also had a great deal to say about their vocational experiences after graduating from the program. Many of them, as you saw in Sweet Girl's section of the preface to this writing, find their work to be an enormous source of pride and self-identity. At the same time, nearly all of them expressed dissatisfaction with a legion of work inequities that included low salaries; instability; poor or unpleasant work assignments; insufficient weekly hours; lack of job availability; few or no career ladders, and little promise for employment beyond menial labor. Choi's work stories illustrate some of these inequities:

> I worked at a pizza place as a dishwasher. For two years I worked there. Then they tore down the building so I lost that job. Then I worked in the garden and outdoor section of [a home improvement retail chain store]. I was there for two more years. But then I moved to another state with my parents for a while. I got another job in a pork processing plant. The dead pigs were all hanging from hooks on a moving line above us. It was very cold in there. We cut up the pigs, took out their insides, stuff like that. I only worked there for six months before I quit. Now I don't have a job, but I am meeting with my VRS (Vocational and Rehabilitation Services) work coordinator and maybe will find something soon.

Angel's employment challenges have been similar:

> I quit my job at (a retail discount store) because they did not give me enough hours or enough pay. Now I'm not doing anything. I'm looking

> for a job with more hours and different [responsibilities]. I am filling out applications but also checking into different places I might like to work. I don't always understand what I'm supposed to know. And if I have no experience, then forget it!

Some of my higher-need graduates including DJ, Cameron, Sweet Girl, and Scooter have had successful, albeit more "sheltered," vocational experiences. These individuals began work in a site-based, piecework facility supervised by employment trainers. Once they performed these tasks to the supervisor's satisfaction they were "promoted" to join a cadre of other special needs adults on community-based assignments. These crews, led by a job coach, perform tasks (usually custodial) in places like restaurants, hotels, or nursing homes. All of my study participants who reported community-inclusion work like this spoke proudly and positively about their experiences. None of them felt shame or disappointment about the jobs available to them and, in fact, could not imagine doing anything else. As DJ explains:

> My goals and dreams are to work with my staff and program here and then in the distant future I will retire. I am happy with what I do now. I want to stay where I am. I like my work and my life.

Many of my graduates had plenty of stories about the work they do and have done in the past, as you could see through Sweet Girl and DJ's interview narratives. Others (like Angel, Choi, and Ken) shared work experiences in which they quit or were let go due to low hours or employers' inability to keep them on staff; most of these participants had not yet found work during the time of our interview. Others who remain at their jobs, like Daniel and Sky, cite poor wages or low hours as part of their vocational frustrations.

What most interested me, however, was the fact that very few of my participants were able to envision or articulate the kind of work they might desire long-term, something they could identify as a career. Scooter exemplifies this difficulty in an exchange we shared during our interview:

> LD: Do you have a special job, something you want to do in the future?
>
> Scooter: (thinks…scratches his chin) I forget…
>
> LD: Well, you know. Lots of the jobs you did before were cleaning, custodial. You think maybe you want to try something different?
>
> Scooter: Well, I'd prefer another, but … like … wait … I'm thinking … I prefer … like … maybe a movie theater!
>
> LD: Oh, I see. You want to make the popcorn? Sell tickets?
>
> Scooter: Well, no: cleaning!

Given the wide variety of work exploration opportunities my graduates experienced both during and after their years at Cosmos, I am unsure why many of them appeared to struggle with ideas about what kind of work they might like to do in the long term. Perhaps some of the students already enjoy the work they are doing and, content with this, do not see the need for a change. In other cases, a lack of job seeking skills or appropriate communication supports and adaptations may create barriers too large to overcome. Still others may be unable to match their skills and interests with future work ideas or are have trouble making the connection between those skills and the work options available to them. Sufficient support and training during school as well as ongoing connections between schools, curriculum, and community agencies may be indicated here since most of my graduates seemed to need more vocational support than they had received.

Transition: Mobility

Training at Cosmos. Whether at a JOBS site or through other transition lessons, Cosmos D/HH students spent a great deal of time out in the community. There they accessed relevant public resources such as the public library or retail businesses in their home neighborhoods. Students traveled extensively via the city public transportation system and devoted countless hours to learning different transit routes, understanding the time tables for the system, and practicing orientation skills (i.e., which side of the street should they board to go in the direction they intend?).   Once again, most of my participants spoke very highly of mobility and community training; in fact, it was one of *the* most emphasized and powerful transition experiences students recalled. Sky narrates:

> Going on the city bus, learning where everything is, recognizing street names, all of that was especially worthwhile for me. It was helpful knowing how to go from school to my home or what was around in my

> neighborhood, how to get to a friend's house. I think all students should learn how to use the city bus.

Daniel adds:

> Mobility training was a huge bonus because I can easily get myself wherever I want to go. Now I am out [using the buses] every day.

Experiences of Mobility after Cosmos. Nearly all of the graduates I met with confirm experiences similar to Daniel's and report they are highly independent and mobile in their post-secondary lives, mostly because they are savvy users of public transportation. In fact, DJ greatly impressed those of us attending the spring picnic this year when he arrived at the park on his bicycle; he had hauled it with him on two different city buses and then pedaled the rest of the way just to get there that day!

Only one of my study participants, Choi, has a driver's license. Few others of my graduates have their license, though some indicated a wish to achieve this goal:

> I want to drive. I've started drivers' education. I'm studying, learning the rules for driving, and then will take the test, get my license, drive in the future. I don't know if I will get my own car or not, though. I know I must save my money and use it for what is important (and maybe a car is not important). (Sky)

The rest of my graduates appeared content with the transportation and mobility options currently available to them (i.e., Sweet Girl, who mentioned getting rides from her group home staff and Vue Pao, who is driven around by his family) or did not mention mobility during our interview.

Transition: Independent Living

Training and Practice at Cosmos. Home, community, and leisure skills are also emphasized heavily in the Cosmos D/HH program. As an example, I personally spent a great deal of time with students discussing food (i.e., their names and how to sign them), healthy snack or meal planning, grocery shopping, and cooking. Every week we would develop ideas for what we might like to cook or eat. Often I tried to incorporate meal ideas that students would be able to make on their own. Other times we would do "comparison cooking" to determine whether brand name—and therefore more expensive—foods tasted better than their generic counterparts (they rarely did). I also included preparing food that students had never tried before such as pomegranates or dishes that allowed students to share a part of their cultural heritages (which was a personal favorite). We would then take the city bus to a local grocery store, make our purchases (with funds provided through transition grant dollars), and prepare the meal in a "kitchen classroom" at Cosmos. These meal-related activities took place over several hours each week and were popular with many of the students. Vue Pao recalls:

> Cooking and shopping were some of my favorites. We would do the shopping [at a large-chain grocery store] and then cook the food for lunch time. Cooking was one of the most helpful things I learned at school.

Living Situations after Cosmos. Through my continued contact with a large proportion of Cosmos graduates (even those who were not interviewed for this study), I have been able to follow up on our students' post-secondary living situations. A small percentage of Cosmos D/HH grads eventually end up living independently or semi-independently in their own apartments or through assisted living apartment programming. A handful of graduates move into group homes paid for by state or county funds. The largest numbers of them, however, remain with their families.

In the case of my study participants, I again refer you to Table 1 (on page 36 of this dissertation) for information about their current living situations. To review: three were living in group homes (Cameron, DJ, and Sweet Girl) at the time of our interview. Scooter had also lived in a group home for a while, but has since moved back in with his family. The rest of my participants continue to live at home. Nearly all of them, however, expressed a wish to live independently. Angel sums up these collective feelings when she states:

> It's boring here at home. I want a change. I want independence for myself, to get an apartment. I want that so much! I wish it, to live independently. First I need to learn different things, to figure out how to take care of myself. To live independently, I need more training. But it's hard for me, hard to expand. It's hard to know all the words in English. I read but don't understand everything; there are words I've

> never seen before. I'm not skilled enough. Inside it makes me feel frustrated.

There was a noticeable incongruity between students' skills and wants as they related to independence and home life. For example, Angel expresses a strong wish for more knowledge or training about independent living skills but she is not granted this knowledge through family opportunities. She might be assigned housekeeping chores or assist her mother in meal preparations, but Angel is not given complex tasks at home such as budgeting responsibilities or practice understanding typical bills and other paperwork common to household management. Such disparate experiences are echoed by my colleague, Thomas, who frequently exclaims that "too much is done *for* these students; they are never given the chance to *do for themselves*." The experience and practice students need to live independently is seldom granted because such skills are not expected of them.

Indeed, by their own report, home and family expectations for my participants are not very high. Few mentioned performing regular chores and most suggested they either observe others taking care of things around the house or they contribute minimally, as in Vue Pao's case:

> Sometimes my mom has me cook rice; she teaches me how to cook rice and other food stuff. I know about chopping meat and vegetables.

Of the study participants who live in group homes, all of them reported regular contributions toward necessary household tasks and therefore seemed better equipped to manage daily living tasks. DJ explains:

> I clean here at the house, the chores are shared by all [the residents]; everyone joins in. There is a list of chores we are assigned and we can check them off once we do them. I take care of the cat here. I do my own laundry plus some of the shared laundry like towels. I clean the bathroom and my own bedroom. Lots of things like that.

There are several possible explanations for the disparity between my graduates' desires to live independently and their day to day realities that do not adequately prepare them for independent living. First, families of exceptional children become very accustomed to taking care of their special-needs child and frequently this attention becomes overly done. Ytterhus, Wendelborg, and Lundeby (2008) report that children with disabilities grow accustomed to this "over-involvement by adults and [lose] their autonomy" (p. 634). My colleagues and I regularly observe this same phenomenon in our students who are very used to having things done for them rather than left to act independently. Next, the majority of my students do not enjoy effective communication with their families, particularly the deaf students whose parents have not learned to sign. These communication limitations, which are stressful for all concerned (e.g., Åsberg, Vogel, & Bowers, 2008) could sufficiently stymie any efforts parents may wish to make to include their MCDHH children in home living skills development. Finally, it is important to note that desire does not always match facility: as much as my students may dream of living on their own, some of them do not possess the cognitive, developmental, physical, or financial resources required to do so successfully.

Nevertheless, the fact that nearly all of my participants, including those who live in group homes now, expressed a desire to have their own apartments or live more independently warrants our attention. Their narratives suggest that more must be done in families and in schools to provide opportunities for independent living skills practice and development before such dreams, when appropriate, can be realized.

Extra-Curricular Opportunities

As with transition programming and mobility training, my graduates likewise identified a number of extra-curricular activities they enjoyed immensely at Cosmos. Many participated in these for several years. For example, Daniel referred to his years with the Gay-Straight Alliance (GSA) at least three separate times in our interview; his summary of that group was this:

> The GSA was really great. I joined from 10th through 12th grades and near the end I was one of the leaders. It was fun and I really enjoyed that.

Other students frequently remarked that adapted athletics (sports opportunities for students with disabilities) were a highlight of their high school years. Sweet Girl explains:

> I was a cheerleader [for the adapted sports teams]. I remember my cheerleading coach. Also, I was a leader for the other cheerleaders; I taught them the cheers. We cheered the home games for soccer, floor hockey, and softball. I also played on the [adapted sports] bowling team and I got a Cosmos letter jacket for bowling—it was an expensive coat! I also won medals [in state tournaments] for bowling. Even now after school is ended I still go bowling and I still win trophies and contests in the game.

DJ was also very active in adapted athletics. Even when he became too old to play (by state regulations), he acted as a manager for many of the teams. He was proud to help coach the athletes, bring water and towels to the players during time outs, or otherwise contribute to the activities he loved so much. Ken likewise shared that adapted athletics stand out as highly memorable and he described the different teams he had been a part of when he attended Cosmos:

> I played soccer, hockey, and was on the bowling team. I was good at them and did them for a long time. My mom couldn't always pick me up after the games but that didn't matter because I could go home on the city bus which is what I usually did.

Most of my participants mentioned a full social calendar and long list of activities they enjoy in their free time now, even years after graduating from Cosmos. For example, virtually everyone I talked to mentioned their usual choices for recreation and leisure pursuits such as visiting friends, going to the movies, or shopping at the mall. In contrast to the home living dilemma explained above (i.e., an incongruence between what the students want and what they can do), the same was not true for my participants' use of free time now that they have graduated. Few of them directly correlated their school activities to the lives they now lead, but some, as you saw in Sweet Girl's story about bowling above, were able to connect their schooling to their lives today.

Special Events

Finally, we have arrived at the last big schooling theme my study participants repeatedly—and quite enthusiastically—highlighted: special events. This category of stories was, without exception, the one most frequently mentioned by all my graduates as highly memorable and beneficial elements of their schooling. These events included dances (e.g., D/HH-specific dances with students from around the metro and the annual JOBS program banquet), field trips to places like a local natural area or to see a theatrical play, and the annual winter holiday party and spring picnic.

These last two events, the winter holiday party and spring picnic, are hosted by current Cosmos D/HH students and staff; all program graduates are invited to attend. They were developed in part because the staff wanted to create and maintain a form of community between current and former students. These events also were, and still are, helpful because they reduce the number of "drop by visits" graduates would often make (which can be disruptive to current students and our efforts to teach). The holiday party and spring picnic are highly-anticipated by all students, former and current alike. Every one of my study participants mentioned at least one—and usually both—of them during our interviews. Several of the graduates took advantage of our meeting to ask me the date of this year's spring picnic and to assure me they would be there. Angel used the final moments of our interview to discuss the picnic; my field notes read:

> As I was tying my shoes and finally on my way out the door (after a two and a half hour interview that I worried had sorely taxed Angel's family; I wondered if I had overstayed my welcome), Angel asked me for the date of the spring picnic. I was very happy to provide it. She commented how she must be sure to remember that date, that she would look forward to it; it did my heart good!

I truly was moved by Angel and her words about the picnic and my reaction was powerful on several levels. For one, I felt great pride and happiness for her, for me, and for the work we do at Cosmos. I was gratified that Angel still cared about staying connected via these special events we arrange for our graduates. The jaded or cynical side of me could argue, "It's just a silly picnic at a neighborhood park. We cook burgers on the grill and let the kids chat with each other or play basketball; what's all the fuss?"

However, the other, more student-attuned me knows just how big a deal these events truly are. I know how eagerly the picnic is anticipated, and by how many people. The kids are talking about them months in advance, sharing dates and times with one another over Facebook, text, and video phone, and we have an increasingly high number of attendees annually. The conversations or what happened at these events are discussed at length by the students and graduates for days, weeks, and sometimes years afterward.

Photographs taken there are pored over again and again. Often memorable events (like the water balloon and squirt gun fights or the time we stood under the park shelter in an hour-long downpour) are just as highlighted as the more mundane (like posing for the group photo). As far as these events are concerned, *everything* matters. To me, this is a striking and vivid example of the role “community” can play in schooling, curriculum, and instruction. When we build in opportunities for community, the impact of our efforts may surprise us for their reach and power.

I believe such community-building within our curriculum or instruction choices is mandatory for teachers and the system of schools. Over the years I have observed my MCDHH students (both past and present) as they sought various places where they might fit in. It is difficult to find groups to which my students feel they belong because there are so few people like them; my current students might lament that “so much of the world is hearing,” but they rarely consider how unlike other people with a hearing loss they might be. There are not many D/HH people who share the multiple challenges lived by my students and research participants (i.e., racial marginalization, co-occurring disabilities, experiences with immigration to the U.S.). Because of this, I believe the need for community is even stronger for our students and graduates: Cosmos is one of the places these individuals are accepted, understood, and welcomed and demonstrates another way schooling can enrich the lives of MCDHH people.

One Last Thought

Approaching the end of this chapter I ask myself, “Well, now what?” That is, I wonder what we can gain from my graduates’ stories about their schooling and how that impacted their lives beyond Cosmos. I had wondered if the programming students received was beneficial or made a difference in their lives. From the narratives I collected, stories that were loaded with lived experiences related to work, mobility, independent living, and the other themes in this chapter, I can make the case that Cosmos D/HH programming has an effect on the lives of MCDHH students. Nevertheless, I frequently struggle with “teacher’s guilt” and the sensation that we never do enough for our students. This guilt can sometimes overwhelm me in the face of my MCDHH students’ chronic multiple needs. At the same time, I know that teachers and schools are not singular solutions, nor can they work in isolation from the other systems or agencies that are in place to serve MCDHH individuals. Rather, there must be cooperation, continuity of care, and a method for filling in the gaps inherent to disconnected institutions; integrated and symbiotic systems are necessary. I will discuss these ideas further in chapter six. First, though, I have another story to tell, and it belongs to Cameron.

Chapter 5: Learning to Teach

We don't, any of us, really matter.
But we do make a difference. – Joel Jacobs

Cameron's Story

As you know, the participants I used for this study are all former students of mine and each of them has had an undeniable impact on me. Their influence reaches across my teaching practice all the way through to this dissertation. In addition to insights from my years of experience with each student, I have drawn on data from interviews and, with some graduates, our continued communication long after we met for this study. Cameron, however, was different. Despite my knowing him for more than a decade and my intentions to conduct his interview the same way I had done the others, his contributions to my research were notably unlike the rest. While this was initially troubling to me, I came to realize that Cameron's atypical participation was actually a blessing. He helped to illuminate some of the ideas about "learning to teach" that had been percolating in my mind as the work progressed. That is to say, Cameron's lived experiences best illustrate what my students taught—and continue to teach—me about educating MCDHH children. Therefore, I begin this chapter with parts of his story, as seen through my eyes.

In School. I met Cameron on my first day of teaching, in the fall of 1999. He was an eighth grader in the Cosmos D/HH program that year and in addition to working with Cameron for several hours each day in the classroom, I was also his Individualized Education Plan (IEP) manager. I performed these duties for the seven years he attended Cosmos (Cameron “aged out” of his legal rights to a public education in 2006, the year he turned 21). IEP management is one element of most special education teachers’ work expectations and involves completing the copious assessment, progress monitoring, and paperwork requirements for all students who receive special education services. It also means coordinating the IEP team which comprises the student, parent/guardian(s), and service providers involved in that student’s life. In Cameron’s case, his service providers included classroom D/HH teachers, a speech and language clinician, district audiologist, school social worker, county social worker, school nurse, adapted physical education teacher, parent (his mother), and group home staff members a few years later. It truly did “take a village” to educate and care for Cameron. In the end, IEP managers are responsible for countless tasks both large and small, but the most important thing to know about that role is this: if anything hits the fan, requires immediate attention, or goes wrong, the IEP manager had better know what to do about it.

As a result of these additional responsibilities, I was always closer to my students for whom I was also the IEP manager and Cameron was no exception. In fact, over the years, I came to know Cameron and his family extremely well; I spent countless hours working with and for him. This work was sometimes direct, as in our classroom and community-based teaching and learning hours. Other times the work was more indirect; for example, I cannot tell you how much time I spent on the phone sorting out transportation errors that left Cameron (and, often, me with him) standing on the curb waiting for his ride long after everyone else had gone home for the day.

Multiple Medical Needs. One reason Cameron was so labor-intensive is because he was born with several medical challenges that left him quite physically fragile. These challenges include heart and valve dysfunctions, renal and gastrointestinal disorders, food and eating issues, and severe undernourishment and underweight concerns (he was just over five feet tall but rarely weighed more than 85 pounds). He has already endured two kidney transplants and is currently on dialysis awaiting a third. Cameron has a hydrocephalitic shunt that is visible through his closely cropped hair as well as countless scars, all remnants from other medical procedures like a tracheotomy and feeding tube. He has spent an exceptionally large amount of his life in a hospital.

Language Needs. Cameron also has multiple language/communication needs that are largely due to his hearing loss. He is the only person in the family who is deaf, though his mother and two of his siblings are hard of hearing. English was the primary language in the home and ASL (American Sign Language, which is Cameron’s first and most accessible language) was used only minimally, and only when shouting or gestures did not work. As a result of limited sign use in both his family home and his group home later on, the majority of Cameron’s language learning and development happened only in school. I very clearly recall that several days following school breaks (i.e., winter holidays, spring break) all of Cameron’s language class time needed to be spent recovering what he had lost while he was away from the communication-rich school environment.

Cognitive Differences. Cameron also has moderate-to-severe cognitive delays which manifest in multiple ways. For example, he has never been able to consistently write his name and address correctly or independently, he requires extra time and repetition to learn most anything, and his interests are not always age-appropriate. It is also possible that Cameron's age-inappropriate behaviors could be correlated to his hearing loss, language deprivation, and the resultant communication gaps that left him unable to incidentally learn social cues. In any case, Cameron's cognitive delays will, of course, have repercussions on his way of life including the kind of work he will do, the kinds of supports he will require to do them, and the need for careful, attentive individuals who will look out for his interests and welfare in the long term.

Cameron's Family. Adding more to Cameron's already-overfull plate I can report that he has several family-of-origin issues as well. Cameron is the second of four children and the only boy. He does not know his biological father nor was there ever a male role model in the home when Cameron was growing up. His race is Black, his ethnicity is African American, though if Cameron experienced racism or biases as a result of these, it is unlikely he was aware of it due to his multiple exceptionalities.

Cameron was raised by his mother who had difficulty finding and keeping work due to child care responsibilities and transportation issues; she did not drive and lived in a River City suburb which made using public transportation more complicated. Cameron's mother also dealt with her own mild cognitive delay. Virtually all of the family income came from county and federal funds as Cameron, his siblings, and his mother all demonstrated special needs.

When I taught and worked with him, Cameron's mother practiced the faith of Jehovah's Witnesses. This often created conflict and confusion for Cameron who did not understand or practice this religion himself. For example, Jehovah's Witnesses do not celebrate Christmas, and his mother left strict rules for school and group home staff about not including Cameron in holiday functions (i.e., buying and giving presents, tree-trimming). This was incredibly difficult to have to do and Cameron, not actually practicing the same faith himself, never fully understood why he could not participate in these activities.

Cameron's mother recently moved out of the state. She made this move without telling him (she left that for the group home staff to do), nor did she stop by to see him on her way out of town. This, according to his group home staff, upset Cameron for several weeks afterward. Though Cameron was never in very regular contact with his mother as it was, he still took the news of her move quite hard. This was evidenced several times during his meeting with me when I noted he seemed to almost perseverate on her, frequently signing what could be translated as, "Mom. Mom is very far from here."

Current Living Situation. I have mentioned Cameron's group home several times now so you may be ready for the full story. Around the age of 17 Cameron, with the support of his county social worker and his mother's blessings, moved away from his family into the group home where he still resides. This group home was selected because of Cameron's multiple medical needs; the staff there specialize in providing care for adults with severe, chronic physical and cognitive disabilities. While they do a very good job serving Cameron and the other residents' physical needs, communication has remained a challenge and something that has been dropped in Cameron's life. Just as it was for him in his family home, sign language is used only minimally because most of the group home staff members do not know ASL.

When Cameron moved in to that group home I was hired by the director to teach the staff key sign language vocabulary and familiar or often-used names and signs to help them know and understand what Cameron was trying to tell them. This worked very nicely for a while; most of the staff seemed to enjoy knowing how to communicate and interact with Cameron who was always a charming, funny young man. However, staff turnover at group homes like Cameron's is often quite high and only one staff member—the group home nurse—who participated in the sign language training I led is still there today (though her sign skills are below average and once during my visit made a very incorrect translation of something Cameron was saying. This suggested to me that he is seldom understood when he attempts to communicate, particularly since Cameron is not fluent enough in English to make note-writing a viable communication option for him).

Interview for this Study. When I arranged our interview, Cameron's group home director alerted me to the fact that he had recently been ill and was hospitalized for heart and kidney difficulties several times in the six months preceding our interview. Since those hospitalizations Cameron had not returned to his work with a day program because he could not meet the requirements of washing his hands (his work team is at a restaurant; some of his staff believe his refusal to follow hygiene protocols is deliberate but they cannot explain his motivation for this behavior). He also was suffering from severe fatigue and could not stay awake during the entire work day. I was told that

Cameron had become despondent, withdrawn, and less communicative than usual. His staff believed he was depressed and had "forgotten" a lot of his sign language; they hoped my visit would be a jump start to get Cameron interested in his daily life and activities once more.

The first time I saw him on the day of our interview was like looking at a ghost of Cameron's former self. He was sitting in a chair in the living room, holding a small toy airplane and staring rather blankly at an afternoon television cartoon program. He was wearing a jacket and stocking cap, even though the room was quite warm. When I teased him about this, he immediately took off the hat (but kept on his jacket); a staff member told me he was "always cold." Cameron did not express any emotion about my arrival; he appeared neither surprised nor happy nor upset that I was there, though I had not seen him for over a year and his staff claimed he had "been looking forward to my visit" (how they know this is unclear since I did not observe any complete communicative exchanges between Cameron and the group home staff during my two hours there).

Before Cameron's visit I had completed all of the other interviews for this study except for Vue Pao's. I therefore had some practice doing the interviewing and quickly ascertained that Cameron was not going to tell me things like his age (25) or the name of his elementary school (Lake Elementary), though he did remember his preschool and Cosmos and was able to share more about himself and his thoughts as my time with him went on. It seemed as though Cameron needed to "warm up" and remember that he could talk to me. It was like he had fallen so out of this practice that getting back into it again required time; I had not anticipated this. When I realized what was going on and that a warm-up was needed, I took him to the computer and showed him photos I had uploaded to the internet of a picnic he had attended a few years before. He recognized himself, some people from school, the park, and the picnic as an event he always enjoyed; he started to behave a bit more animatedly than when I first arrived. Then he began identifying more of his former Cosmos staff and classmates by name. In the case of the latter group Cameron even started to call up some of the gossip he used to tell about them (i.e., who had been dating whom, who made him laugh). Slowly, slowly, the spark that used to be inside the Cameron I knew began to glow again.

Right around the time I saw that spark returning I decided that my “researcher’s hat” was inappropriate for this visit with Cameron. Instead, I would return to my role as an advocate; something I had done constantly in the years I was his teacher and IEP manager. During this visit I used our time to try and elicit responses from him about what he might want to eat or how he might like to spend his recreational time since his staff had been unsuccessful in their attempts to extract this information from him. I believed this new focus was more important for Cameron and his immediate situation so, without hesitation, I dismissed my intended research interview plans and attempts to obtain his narratives.

After the fact, and as a result of feedback and comments from readers of this chapter, I have revisited my decision to assist Cameron and his staff (rather than attend to my study) several times. Some have suggested that ignoring my research must have been a conscious decision to effect change, work for social justice, or whatever else social justice researchers do in their work. This may be partially true, I suppose. What I’m more sure of, though, is that I acted on reflex. Stepping in, acting on Cameron's behalf, and working to increase his communicative exchanges are second nature to me: I have *always* done so; why would this visit be any different? I think what happened is that my visit with Cameron helped show me that I am driven by social justice issues as a teacher and researcher; the teacher and advocate part of me is just more automatic.

As it turned out, I was able to be both a teacher and researcher during my visit with Cameron that day. That is, I was able to facilitate communication, advocate for him and his needs, and get his answers to all the questions his staff members asked him. I was also able to collect some of Cameron's thoughts and feelings because during our time together he occasionally produced poignant, sometimes heartbreaking, narratives like those related to his mother's move. There was also this one:

> I was in the hospital and my sister was there, she saw me. She is strong, healthy, not thin and weak like me. She even gave birth but she is still good, normal. I am always skinny. I am always weak. In pain. Sick. Again and again, every day, all the time I am sick. Hospitals. Dialysis. My heart. I am sad, angry. I am always sick.

This was the first time I had ever seen Cameron express emotion about his physical health problems. It was also the first time he expressed a wish for change. I did not know how to respond when he told me this story, other than to sympathize and tell him I was sorry. Which did not feel like, and certainly was not, enough.

Learning To Teach Urban MCDHH Students

Cameron’s story illustrates many of the “learning to teach” ideas that have simmered in me since before I began doctoral study. I have discussed several of these themes and ideas in earlier chapters. For this chapter, I wanted to address more of the ways I see my teaching practice guided, constructed, and adapted by my students. When I reflect on the nature of the work I do at Cosmos, I have certainly needed teaching skills like pedagogical knowledge, instructional strategies, content knowledge, classroom management, and pedagogical content knowledge that are important for all educators (e.g., Cochran-Smith & Zeichner, 2005; Darling-Hammond, 2006; Darling-Hammond & Bransford, 2005; Shulman, 1986). I also, of course, have needed the knowledge and skills that are specific to working with students who have a hearing loss (e.g., Cerney, 2007; Marschark, Lang, & Albertini, 2002; Marschark & Spencer, 2003; Moores & Martin, 2006; Spencer & Marschark, 2010).

At the same time, there have been other skills that I discovered were imperative for success in my work with urban MCDHH students, but were not obvious nor directly taught to me during my teacher preparation. Instead, these essential traits evolved as a result of my experience with the kids in River City Schools, and emerged regularly in my research interviews with them after their graduation. Two such “above and beyond” teacher attributes relate to communication and advocacy. I will explore both of these characteristics and share narratives that illuminate their importance in the next sections.

Learning to Teach: Attention to Communication

Common Language and Easy Communication Is Not A Given. One element of Cameron's story that may have stood out for you is the fact that he never lived in places where easy communication was the norm. While spoken English was always used in both places, this was not helpful to Cameron who is deaf and does not access spoken language. ASL was not used in his family home, nor is it used in his group home now; communication was always reduced to gestures, facial expressions, and a lot of guesswork. Cameron's battle for equitable communicative access has been ongoing for at least as long as I have known him.

In fact the majority of my students and graduates live, like Cameron, in stunted or anemic communicative environments. While the deaf students who do not access any spoken language are going to feel the sting of this reality more strongly than my hard of hearing students will, both groups of students acknowledge the struggles that language and communication challenges have created for them. As my participants explain:

> There is no one to talk to or to help with communication when everyone else is hearing. I don't understand them. (Sky)

> Communication is very hard, I don't understand people. I must write notes, but they are not always effective. If there is a safety concern like an alarm or warning bell, I am at a disadvantage. (Angel)

If I didn't see it every day, I almost wouldn't believe such a situation was even possible. I ask you, how basic a human need is communication? How much do we all take easy communication for granted, consider it our birthrights as human beings? How could teaching and learning take place without human communicative interaction? And how could this essential need possibly go unmet? In over ten years instructing dozens of MCDHH students who experience language-deprived lives similar to Cameron's, I am appalled and outraged by these circumstances. Yet they remain realities for so many of my students who regularly struggle with language, and often on several levels due to their multiple challenges.

The edge to my anger has dulled somewhat over time, though. This could be because the constant, wearying grind of repeatedly encountering this situation has worn me down a little. I also understand that sometimes my students' families, particularly those who are immigrants to the U. S., have larger, more urgent needs (i.e., finding work or safe housing, learning English, feeding their families) than learning *yet another* language for just one of their children. Further, I believe the stories could be different if my students and graduates came from homes where their first language was the same as the rest of the family. For example, it might be different if my deaf students had deaf parents.[1]

School is sometimes the only place my students' language and communication needs are met (at least somewhat comprehensively), and the Cosmos D/HH program has attempted to fill in the gaps whenever possible. As a teacher, I have learned that I need to sometimes be a voice for my students. More importantly, though, I must teach kids to find and use their own voices and how to do so within the confines of a world that is structured around being able to hear. For them, easy communication is not easy.

Persistent, Chronic Separation and Isolation. You may have also noticed in Cameron's story that he often appeared left out of various decisions that impacted him (i.e., the ways religion would be practiced in his family). He was omitted from such decisions largely because no one could sign fluently with him and he did not share his family's primary communication mode.

It was also true that Cameron's multiple needs were prioritized and language was rarely put first. For example, when he moved to the group home, his communication needs were shunted to the side because health and medical ones took precedence. Had he been moved to a group home with signing staff and residents, his medical issues may not have gotten the care they required, and it was determined that his health came first.

Cameron is not alone in this dilemma. In my work and experiences with River City students it is rare to find a child whose needs are fully met all of the time; language and communication are almost always the first to go (or to be left the school's responsibility). These realities can create a sense of persistent, chronic isolation and separation from others, particularly outside of school. As Harold A. Johnson, a prominent researcher and teacher trainer in D/HH education states, "It can be argued that the essential problem of deafness is not a lack of hearing but an abundance of isolation" (2004, p. 76).

Such separation is mentioned regularly in the literature (i.e., Cerney, 2007; Spencer & Marschark, 2010) as well as in the memoirs of people with a hearing loss. For example, Helen Keller is credited with saying that "Blindness separates people from things, but deafness separates him from people" (Alabama Institute for Deaf and Blind, 2009). Henry Kisor (1990) has a slightly different spin on this issue when he writes, “Deaf people share certain similarities with blind people, for each has suffered the loss of a sense. Our afflictions, however, are not the same. The consequences are profoundly different. Blindness is a handicap of mobility, deafness one of communication” (p. 10).

Either point of view makes it very clear that disconnection from others because of unreliable or dissimilar communication modalities is a common, and often dominant, feature of life without typical hearing. It is very true for my MCDHH students in River City. As their teacher, I have had to learn when and how to prioritize my students’ communication needs. I have also needed to teach these skills to the caregivers and important people in my students’ lives who do not always recognize the isolation and separation inherent to hearing loss. The barriers to effective communication must be brought down or their negative effects will persist. Over the years I have learned to spend extra time with my MCDHH students with the goal of removing (or at least lowering) these barriers. Some of the ways I do this are to practice note-writing for communicating with people who do not sign, to increase functional reading skills so students can access important information independently, or to encourage them to teach some signs to their hearing family members and peers so they might feel more connected to the people around them.

Social Skills Development and Age-Appropriate Interests. Another item significant to Cameron’s story is that on the day I arrived to interview him, he was watching a cartoon and holding a toy. Likewise, he did not follow conventional behaviors when a visitor arrives; for example, he did not greet me when I walked in.

Cameron is 25 years old, so these features of my visit are examples of ways he has not developed age-appropriate interests and social skills. Many of my students and graduates are similar to Cameron in this regard. Spencer and Marschark (2010), summarizing research in the field of D/HH education, suggest that social-emotional differences in D/HH individuals could be, at least in part, attributed to language delays since these:

> Can interfere with a child's acquiring words or signs needed to accurately communicate and understand various emotional states and, more generally, can interfere with general parent-child and sibling-child communication [where these skills are usually first learned] … Difficult social interactions beyond the family settings have often been reported when deaf and hard-of-hearing children did not have sufficient numbers of peers with whom they could identify and communicate easily … some researchers [suggest] that children with hearing loss may be generally neglected or isolated (p. 19).

Thus, a D/HH child's way of negotiating complex social expectations may be weakened or minimized due to differences in socio-emotional development precipitated by language differences. An MCDHH child may experience these difficulties even more strongly as a result of their co-occurring needs and challenges, such as Cameron's cognitive delays.

As their teacher, I have learned the value of devoting extra time to helping my River City MCDHH students build more age-appropriate social skills. One particularly effective way to do this has been to mirror students' inappropriate behaviors back to them. When they watch me rudely push someone aside to clear my way or fail to hold open the door for them when their hands are full, they "get it." They very quickly correct me and delight in showing me how they know so much more than I do. In addition to enhancing students' social skills, this has been a marvelous instructional tool for me and a wonderful way to enrich my relationship with these kids who love to learn through laughter.

Therefore, though not necessarily emphasized in teacher preparation, attention to language and communication needs has emerged as central to my role as a teacher of urban MCDHH students. These skills include helping students represent themselves and find their voices while negotiating a hearing world, reducing the isolation and separation that comes from communication differences, and developing age-appropriate social skills.

Learning to Teach: Teacher Advocacy

Connecting Service Providers and Ensuring Service Continuity. In Cameron's story I mentioned advocacy several times, particularly as it related to my work as his IEP manager. In my teacher training, including the student teaching practicum, I do recall learning the basics for typical special education teacher tasks that I would need to accomplish in my job. I do not, however, remember ever learning about teacher advocacy.

It was not until I was immersed in my work at Cosmos that I came to understand the essential role advocacy would play as a teacher of urban MCDHH students. In my time with these students I came to see how important it would be that I know how to connect them to the agencies and service providers they would need during and after their years at Cosmos. In fact, I contend that teacher advocacy has been one of the most striking and compelling lessons I have learned during my years in the classroom; this has been further illuminated for me during the months I conducted this study. While Cameron's story did, of course, highlight various teacher advocacy themes for me, my interview with Angel did as well; I share that story next.

My Interview with Angel. Truly, the need for advocates in my students' and graduates' lives cannot be understated. To illustrate the lessons learned from Angel, I offer you the notes I took after my interview with her. They are dated January 15, 2010, and were scribbled furiously the minute I got home (though I have cleaned them up somewhat; for example, I removed all of the expletives). As you read, please consider the notion of teacher advocacy and note how often the theme arises in this narrative:

> Angel lives in a cluster of apartment complexes situated along the far eastern reaches of the city. These apartments are home to a large population of East African immigrants, most from Somalia or Ethiopia. I note a rather lax attitude about security in that the door to Angel's building is not locked, nor do I need to be buzzed into the atrium. A man is standing in that space, apparently waiting for someone, and he waves me in with a friendly smile and a gesture toward the stairs (which I take, presuming I should anyway to reach Angel's second-floor apartment). I am a perfect stranger having never been in this building before, so this man's friendliness is nice, yes, but unsettling because not all visitors there will be benevolent ones.

Strong, delicious smells of curry permeate the dim, plain hallway where I pass several young men dressed in jeans and, just as often, shorts. Their attire is strange because this is a Midwestern January, though I concede it *is* quite warm in the building.

Angel meets me in the hall outside her apartment and brings me inside. Following her lead, I remove my shoes, and then we both sit on the floor in the living room for our interview. We are regularly joined by different people who intermittently break into Angel's and my conversation. Most of them, aside from a young man Angel identifies as her brother, are family members who do not know English or ASL. As I do not know Somali, Angel has to translate when her brother is not there. This is accomplished through Angel speechreading their spoken Somali as best she can, then signing to me what they have said. It is dizzying to behold.

The familial interruptions are frequent because these folks regularly want to ask me a question, are seeking clarification and advice, or make a direct request for assistance and even my things (as when Angel's cousin asks if she can have the laptop computer onto which I am typing the interview notes). All of the interruptions leave me feeling overwhelmed, sad, or angry (and sometimes all three). For example, Angel's mother asks me several questions about where Angel can go to school now that she is out of high school (this particular conversation is translated by the brother). Her mother wants Angel to have a future and something to do, but doesn't know how this will be accomplished if "she can't communicate." I am irritated at this statement because mom has been sitting here watching us signing to one another for over an hour; what did she think we were doing if not "communicating?" I swallow my frustration and take a lot of time to explain how I consider sign language to be a viable communicative method. I try to impress upon Angel's entire family how obvious it is that she clearly *can* communicate effectively, but that her mode simply isn't one they are familiar with.

I am challenged by Angel's family's questions on a few different levels. Personally, I am insulted at the assumptions and attitudes they appear to have about D/HH people being "unable." I try to explain about my own hearing loss and that I manage just fine in my work and life and I ask if they might view Angel similarly (my queries are usually answered with a noncommittal shrug). I do not know how to separate myself from these attitudes, even though I think that, as a "good researcher," I should.

I also feel so ineffectual! I don't think I am successful in my efforts to address this family's questions nor do I think I have convinced them of how much Angel can do. I have a hard time letting go of my failure and wonder what I might have done that would have made a difference.

I am also challenged professionally since the questions these folks are asking me are things I had tried to get them to address a long time ago, when Angel was still at Cosmos. In those days I had repeatedly tried to impress upon Angel's family that the time to plan ahead and pave the way for her future was when she was still in school. They had always resisted these efforts and, in fact, hardly ever bothered to attend any of the meetings we held for Angel (i.e., her mother never once attended an IEP meeting).

Of course I realize I do not know all of the circumstances or barriers that may be in the way for this family. For example, I am not sure how our schools and systems do (or do not) make sense in the lives of immigrant families whose cultural viewpoints, notions of time, and expectations of teachers may be very different from my own. But I am still frustrated that my efforts then (when Angel was in school) are not acknowledged until now (when I have less to offer and when I have fewer resources to give or direct the family to get for themselves).

At another point in the interview Angel expresses a desire for a video phone and asks me several questions about how they work, how to get one, and so forth. In all of these explanations I regretfully give her the disappointing news that high speed internet lines are required for a video phone to work and that these lines are different and separate from a conventional telephone line. This upsets her terribly

> and it breaks my heart to have to disappoint her like this (they do not have high speed internet in their home). All the while we are talking I find myself feeling sadder and more guilty and thinking, "She is left here, alone, and with no resources."
>
> Angel's interview goes on for well over two hours, and my roller-coaster emotions are relentless throughout that time. In the end, I realize how overwhelmed with gratitude I feel toward her. This interview is so strong, stirring, and immense that I know I will need a long time to sort through it. I still feel dozens of internal tensions and conflicts; I feel grief, frustration, and worry for her. I also feel tremendous guilt because I know that, between Angel and me, the sole beneficiary of our time together will be me. I feel very helpless and like *the opposite of* a change agent. What exactly am I doing in the classroom and how might I do it better so that, down the road, I do not meet graduates with experiences like Angel's? What will make a difference? Right now, though, I have a singular goal: to consume *a lot* of beer.

I hope the story of my experience of Angel's interview has illuminated some of the messy complications wrought by lack of strong advocates that my students and graduates sometimes experience after leaving school. She is unemployed, lives with her mother, and has very little connection with the outside world. She has few, if any, service providers who work with her. For example, while she did have the card for a Vocational Rehabilitation Services (VRS) work coordinator, this probably did her little good since Thomas, my colleague at Cosmos, later told me that particular VRS employee had retired. Angel has few resources and a family who considers her unable to accomplish much. Like Cameron, Angel is a living and breathing example of someone who seriously needs an advocate.

Just as importantly, these two are not my only graduates who struggle with a chronic lack of support and advocacy after they leave school. What I also hope, then, is that we as educators and service providers for MCDHH individuals will create new ways to advocate for them no matter where they are on the service continuum (I will discuss this idea a bit further in chapter six).

A Few More Thoughts about Learning to Teach

First, I am pleased and excited to report that the teacher attributes I learned through my practice and were reinforced during my research—attention to students' communication needs and teacher advocacy—have been identified as required initial knowledge and skills in the newly revised standards for D/HH teachers (Easterbrooks, 2008). This means that the importance and sheer necessity of these skills may not come as a surprise to new teachers of children with a hearing loss and, rather, such teacher traits may be addressed in their preparation and field experiences. Since I have found them to be of ultra importance in my work with urban MCDHH learners, this was good news indeed.

Second, I still wonder about the connection between teaching, research, and our practices with students. My doctoral training, though liberal and tolerant of multiple avenues for approaching academic work, still has me anxious about the ways I might position myself in such work and in the larger arena of educational research. For example, whenever I felt myself stepping out of what I thought were more traditional academic researcher roles and into the more comfortable and familiar realm of teacher-advocate, I would fret. Oftentimes I did not recognize I had stepped across those boundaries until well after the fact, and then I would agonize over whether or not I could deliver whatever I had promised (i.e., whether I could contact Angel's VRS worker for her). I frequently tiptoed between the landmines that "teacher vs. researcher" had become for me, chastising myself that I had no business stepping into the lives of my participants on the occasions I was wearing the researcher's hat.

But what I want to really ask is: why not? Why can't research and advocacy intersect? Why must my role as their teacher and advocate end immediately once my students graduate? Why couldn't I make phone calls on behalf of Cameron, Angel, or any of my other graduates? Why do systems like schools, vocational agencies, or other community resources that are designed to work *for* people function so separately and independently? Couldn't more work be accomplished if these agencies operated cooperatively and the services were aligned more holistically? What might this mean for those who will be learning to teach?

Chapter Five Epilogue

I was in the middle of writing this chapter when I noticed that an email from Cameron's group home director had landed in my spam folder and, away from my district's email server for the summer, I could not retrieve it. After we eventually made contact I learned that the director had originally written because she needed help and wanted ideas for ways to increase Cameron’s quality of life. Specifically, she wanted to know if I had any suggestions as to how and what Cameron might do to get more social time with his peers, particularly those who were his friends at Cosmos. She was asking for this several months after I had visited Cameron for this study, but I am certain it was my reconnecting with him and including him in my research that prompted the director to contact me (or, at least, to think of me as someone who might be able to help her out).

The director’s email was a positive one and her intentions were good (and quite fitting for me given I was writing this chapter at the time and thinking a great deal about how to keep services going for MCDHH students). However, in the days it took her messages to reach me, Cameron had another setback. He had fallen and been hospitalized. In the hospital he continued to run a fever so they kept him for more observation. Then he started to have seizures, several of them, and over several days. A CT scan indicated bleeding in his brain. He has remained on the intensive care unit where they continue to monitor him and try to figure out what is going on. I cried for over an hour the day I got this news. I suppose sometimes, regardless of how much of a difference we hope to make in someone’s life, we still might not matter all that much. Because the kind of peace Cameron needs—say, freedom from constant sickness—is not something I can give him and wasn’t necessarily anything I could have learned. I sure wish I could have, though.

Endnote

[1] Oddly, this has never been true for a single student I have worked with in River City Schools. I can only speculate on the reasons for this, but it could be because deaf parents tend to send their children to schools like the ones they attended (i.e., state residential schools for the deaf) or because deaf parents do not live in River City (unlikely) or because the deaf parents who live in River City do not have deaf children.

Chapter 6: How Would MCDHH Education Change If Our Stories Were Told?

You may say I'm a dreamer,
but I'm not the only one…
Imagine. – John Lennon

Returning from Whence We Came

So here we are, approaching the end of the work, and at the chapter that traditionally offers "implications for this study." In other dissertations this would be the place where the findings are summarized and extrapolated onto the existing research in the field. In my narrative inquiry, however, I am more concerned with the ways our stories might expand what we already know in D/HH education, particularly as that knowledge relates to MCDHH students. In an earlier chapter I cited narrative inquiry pioneers Clandinin and Connelly (2000) who explain the purpose of this kind of research. I will repeat that quote here as a reminder for us and because I will use it as a framework for this final chapter:

> The contribution of a narrative inquiry is more often intended to be the *creation of a new sense of meaning and significance* [emphasis added] with respect to the research topic …many narrative studies are judged to be important…for the *vicarious testing of life possibilities* [emphasis added] [offered to] readers of the research. (p. 42)

I will also remind you that the key questions I asked before and during this study included:

- What are the lived experiences and resultant stories of my MCDHH study participants? How can I create a venue for the voices of the formerly voiceless, particularly since this has not yet been done in the field of D/HH education?
- What have these participants, who were once my students, taught me about ways of understanding ability, schools and learning to teach? How can their stories shed light on my practice and, possibly, the practice of pre- and in-service D/HH teachers, particularly those who serve MCDHH students?
- What can our stories contribute to the field of D/HH education? How can we expand our understanding of the work we do with people who have a hearing loss? How would my field change if our stories were told?

Thus, in the spirit of creating a new sense of meaning and significance with respect to the research topic *and* to vicariously testing life possibilities, I will use this chapter to explore these ideas once again. I challenge you to test these same themes and thoughts for yourselves and invite you to join me as I imagine what might be next.

Creating a New Sense of Meaning and Significance

In this dissertation I have attempted to share with you some of the many lessons my MCDHH students and graduates have taught me in the classroom, through my years of knowing and working with them in school and community settings, and through interviews and other data collected for this narrative research study. Thus the principal purposes of this dissertation directly address my first questions. That is, I write extensively about my MCDHH students' lived experiences and I use this work to provide a venue for their lives and voices. All it really took was deciding to do it. Well, that plus a generous doctoral thesis committee and an extraordinarily patient adviser.

For my second set of questions, I gave a chapter to each of their elements. In those chapters I examined and discussed how my participants taught me new ways of understanding ability, schooling, and learning to teach. Some of the highlights from those pages include:

Ability

My study participants encouraged me to re-think hearing-centric hegemonies and the ways those of us with a hearing loss can be minoritized in a world that is dominated by people who hear typically. My participants also offered alternative narratives, ones that did not repeat dominant discourses about what it is like to live in a hearing-majority world, and helped me to consider multiple versions of ability as constructed entities that we can then re-construct (or discard altogether).

Schooling

This chapter elaborated on the multiple ways the curriculum and instruction we offered at Cosmos was manifested in my MCDHH students' lives. In many cases, the functional academics and transition-focused curricula we provided appeared to be essential contributors to participants' lives today, particularly in their vocational options, levels of independence, and means for mobility. Schooling can be a place to develop community and a shared history that can have a lasting impact on us all, but it is not the only thing that contributes to whole and well-rounded lives. Other systems and services must also be activated since schooling will not ensure service continuity or the lifelong support and advocacy upon which many of my former students rely.

Learning to teach

Through parts of Cameron and Angel's stories I explored two teacher knowledge and skills I consider essential to my work with urban MCDHH students: attention to communication and teacher advocacy. Neither of these teacher traits were explicitly taught to me during my teacher preparation, but both have proven to be critical to my work in River City Schools. In this chapter, I explain these ideas more deeply.

My final research phenomena, my questions about the implications of this work, and more about the use of these stories will be discussed below. First, though, I wanted to remind us how we got here and the means through which I created these new senses of meaning and significance: narrative inquiry.

The Epistemology, Methodology, and Theory in this Study and Beyond

I return to narrative epistemology, methodology, and theory because I will spend a bit more time with them in this chapter. Earlier in this writing I spell out the multiple theories underlying this study which include narrative epistemology; social justice research; special education constructs; acceptance of "messy multiplicity;" and the importance of including historically marginalized individuals in educational research.

Narrative epistemology, more specifically, involves new forms of knowledge and ways of understanding what we know. Narrative knowing is grounded in experience; lived within temporal, social, and spatial boundaries; and conveyed through story. In the next few sections, I share some of the ways I imagine narrative inquiry can be expanded to create even more new meaning and significance within MCDHH education.

Listening to Often-Unheard Voices: Including MCDHH Students and Teachers in Education and Research

Listening to MCDHH Students. I have made the claim that including MCDHH students in education and research is long overdue. The voices of such individuals are rarely—if ever—heard in my field of D/HH education. There are some researchers who work and write *about* MCDHH learners (i.e., Ewing & Jones, 2003; Guardino, 2008; Jones, Jones, & Ewing, 2006; Knoors & Vervloed, 2003; Spencer & Marschark, 2010), but none of them include these students as research participants. In fact, I have never once encountered research like mine where not only are MCDHH individuals included, but they are central to the study. In this way, my work is unique, but I hope the time has come for research like this to be the norm rather than a novelty. To me it is quite clear: in order for us to understand the lives, experiences, and needs of MCDHH people, we must add their voices to the conversation. Our field must work to be more inclusive of the people we claim to serve, students and teachers alike. Collecting and sharing narratives can be some of our first steps toward this effort, but, to serve our students better, the work should not stop there.

We must also, in my opinion, use these voices and stories to direct our research energies. If we wish to be relevant for the learners our work is meant to serve, then we need to ask what matters so we can know where to begin. That is, what do students tell us they consider important? Where do their stories lead us? What do they say again and again? In the case of my MCDHH participants, the stories they shared about their lives, work, and visions for the future made it clear to me that deaf and hard of hearing students with multiple challenges want the same things that most of the rest of us want. They crave meaningful work with fair salaries and sufficient hours, freedom to travel about on their own, and support to live as independently as possible. They need a relevant curriculum that provides them with the skills required to achieve their individual goals. They depend upon advocacy, accommodations, community involvement, and communicative supports to get what they need.

I do not think any of this is expecting too much, nor does it seem overly burdensome or impossible to attain. Knowing this, I now have a tremendous advantage in thinking about and planning for my next group of students and the ways I could optimally use our school time together. I am only one teacher with one small group of students and yet, to find this out, all I had to do was *ask*. Imagine how many more lives we can touch, how many additional MCDHH students we can reach, if all of us are doing the same things and involving our students more directly in our classroom decisions and/or research.

Listening to Teachers. On a related note, other unheard voices often belong to teachers who remark that educational research is not aligned with their needs or the realities of schooling (Evans, Stubbs, Frechette, Neely, & Warner, 1987; Zeichner, 1995). As a teacher I held and, for the most part, still hold this same point of view. Therefore, including teachers more wholly in our educational research agendas makes perfect sense to me. Of course, because the unique needs and interests of MCDHH students are so close to my heart, I especially want to include the teachers of these students as primary among the educators who might guide MCDHH research. How better to achieve educational research relevance than to listen to teachers' questions and then design our studies to try and answer them? How do we imagine the intersections of practice and research might change if this became a standard in education?

It seems almost ridiculous that I am using this venue, my doctoral dissertation, to make the call (one that approaches a plea) for including students and teachers in our educational practices and research, when common sense tells me this should already be the case. My students' and my real-life experiences, however, do not align with what I think is sensible. My MCDHH students do not have the experience of being included in research agendas and teachers are not usually asked what they would consider relevant to their practice. Imagine, then, how our field would change if they were.

One other anecdote for you: a handful of times during doctoral study my colleague at Cosmos, Thomas, would approach me with a question and ask if there was any available research data to answer it. There never was, and I always felt as though I had personally failed him. This, of course, was ridiculous (at the time), but now that I call myself at least a fledgling researcher, I might need to go back and ask Thomas to repeat his questions and kick-start my next study.

Using Stories. One last thought on collecting, disseminating, and using MCDHH students' (and their teachers') narratives is once again anecdotal and personal (though no less true or, possibly, helpful for this discussion). Somewhere along the line I realized that not once during the many years I spent in my D/HH teacher preparation had I ever read a story written by or about a person with a hearing loss. Not once in my training had I been expected to read anything more than page-long “case studies” about a particular D/HH student. Similarly, I read no stories in the decade I worked as a teacher of MCDHH students, either (perhaps because by then I had a role in my own students’ narratives, and they in mine, so did not feel the loss of story as strongly).

I see this disconnection from D/HH individuals’ stories as rather astonishing; particularly because of how instructive I believe narratives to be (i.e., Canagarajah, 1996; Clandinin & Connelly, 2000). However, as I discussed in chapter three, the absence of D/HH narratives might not be so surprising when viewed through a hearing-dominant hegemony. That is, hearing people are the majority in most cultures and societies and, as such, they decide the content and topics that will enjoy precedence (Cohen, 1994). The field of D/HH education mirrors the hearing majority and, as counter-intuitive as it may seem, D/HH people and their stories may not immediately present themselves as central to the conversations in a profession led by people who do not have a hearing loss. I believe this is an important omission in our field but, at least, one that is easily remedied.

For example, as a doctoral student working on a written preliminary exam that most people will never read, I collected dozens of narratives and memoirs from D/HH individuals. Through my reading I generated a handful of themes that I found had ranged across most or all of the narratives. I then used those themes to suggest ways we as educators may be more effective in our work with students who have a hearing loss. I needed the stories to understand the lived experiences of D/HH people before I could advocate for person-specific change in the classroom. Thus, stories and narrative methodology were extremely beneficial to me and to my thinking about pedagogy.

It has been a while, though, since I have been in a teacher preparation classroom so I am unsure whether narratives have been added to the curriculum there. I can, however, vouch for the fact that they still are not regularly used in my teacher education and professional development workshops. I feel their absence deeply. I wonder what the teaching profession would look like if we added more stories: how many other teachers would benefit from their use?

Shaping our Teaching Practices and Preparing Teachers for MCDHH Students

In the interviews with my graduates I was told, over and over and in a variety of ways, how the transition training and functional skills curricula we offered at Cosmos impacted their lives. It was clear from their narratives that the hours we devoted to such training were indeed worthwhile. While my participants were given extensive transition training and support during their years in the Cosmos D/HH program it was also clear that a great deal more was needed. So, in returning to my social justice theorist tendencies, some of the ways we might effect change in our practices with MCDHH students may include the following.

Ensuring Service Continuity. After they left school, too many of my MCDHH graduates appeared abandoned, barely treading water with inadequate support services, insufficient skills for communicating in a hearing-dominated world, and little or no (or ineffective) advocacy from those who know and understand how to best serve them. As the interviews for this study went on I felt increasingly apologetic and disconcerted. Again and again I saw how quickly my graduates were misrepresented, or consigned to less than ideal situations after departing from the careful attention we had given them at Cosmos. How did this happen; what went wrong? Did we make them too dependent on us and our assistance? Did we not prepare them enough for a world without our advocacy? Were their needs too chronic or persistent to be met by those who remained to care for them? Whatever the case, service continuity, sustainability, and support are other elements of teaching MCDHH students that need more careful consideration and attention. Knowing this, how might we imagine new ways of preparing or training teachers of MCDHH children?

Multiple Roles. Along similar lines, teachers of urban MCDHH children will often find several issues that require their attention on any given day. There may be varied cultural or societal barriers to surmount. There may be language differences (i.e., between parents and their children, between school personnel and family members) that make what could be a simple thing into something quite complex. There may be economic factors, immigration concerns, health and nutrition needs, and transportation snafus. There are policies and paperwork and building/district/state/federal requirements to which we must adhere. There are safety and well-being responsibilities (i.e., should we venture outdoors into a Midwestern winter if none of the kids have hats or gloves?). Oh, and there is, of course, curriculum and instruction to purvey. Indeed, urban MCDHH teachers are busy, and not always in the ways people might visualize us to be. With these students I am concurrently a parent, nurse, detective, social worker, and interpreter, too.

Given these truths, and the fact that I hate to add something to a teacher's over-full plate, I still need to add this: all of these things we still must do. I think a part of teacher education and training should include these realities, these facts of daily teacher existence, and there are multiple ways we might accomplish this. One of the first may be to continue collecting and sharing our narratives and using them in the preparation and professional development of teachers interested in MCDHH students. Teachers are perfectly-placed to do this work and contribute to what is learned in educational research; they should be permitted to join in.

Teacher Advocacy. We also must not forget our role as advocates for our MCDHH charges. I realize I have spent a lot of time and energy on this topic already, but I never feel I can adequately emphasize how important I believe this role to be. Too often I have been the only person able to fill in the gaps left by communication difficulties between families and their MCDHH child. I have needed to act as the link between students and agencies or programs that would continue providing services once the child left school. As a result of my re-joining graduates' lives by way of this study, I have continued this work speaking for (or on behalf of) my former charges like facilitating communication between Cameron and his group home staff and making inquiries with my Muslim colleagues in an attempt to find a mosque that offers sign language interpreting for Angel. I feel a strong responsibility in this regard and will not drop these duties just because I am no longer officially their teacher. Work must still be done so I will do it; in this way, my teacher advocacy responsibilities feel almost like they are *mandatory*. I think we also must prepare and educate pre- and in-service teachers about these same responsibilities and encourage continued attention regarding the importance of teacher advocacy.

Vicarious Testing of Life Possibilities

I have observed children playing an imagination game that involves creating the most incredible, the most fantastic, the greatest and most amazing wonderfulness they can think of, practicality and reality be damned. I wish to do that same thing now. Because why not? And what if my ideas are not so fantastical? What if they *are* in the realm of possibility, if they are something we could envision and then enact for ourselves and our field? If we wish to do something, why not make it the best possible version of that thing? Here, then, are some of my ideas, suggested implications for practice and research, and my own testing of life possibilities that, as a result of my work for this study, I now imagine for MCDHH children.

Re-Thinking Teaching Spaces

What if teaching did not only happen in the classroom? I suggest that teachers *start* by leaving their classrooms and, as much as possible, move beyond the four walls of the school. Go explore the building, learn about the neighborhood, utilize a public space (the library is one of my favorites), drop by local farms or businesses. At Cosmos, teaching and learning regularly took place out in the larger school building, neighborhood, and community and I could not have been more pleased with our results. I think we could have stretched the boundaries even further, though.

For example, I also wonder about bringing teaching and learning into homes and with the people our MCDHH students interact with regularly. It is one thing to tell people what these kids can do, but even more powerful to *show them.* I regularly am not believed when I vouch for my students' abilities, but allowing them to prove my claims in person could speak volumes. This also provides opportunities for increasing communication strategies and skills for all players, demonstrating needs as well as strengths, and generating goals or tasks everyone can work toward until the next time the teacher stops by.

While we're at it, why not also bring the teaching and learning to other places that are meaningful for MCDHH individuals? During several of my graduate interviews I dearly wanted to visit their workplaces and talk to their employers. Or visit with their Vocational and Rehabilitation Services officer to make sure follow-through (or anything else they needed) was taking place. At Cosmos, we often took kids to places where they could get the things they needed (i.e., their state identification card, a job application). I can also, though, envision many more places (e.g., art or theater performances, sporting events, D/HH cultural events) to bring our students that would be meaningful and beneficial for everyone. Therefore, because I encourage teacher advocacy, because teachers tend to know their MCDHH students' needs very well, and because I am working to ensure service continuity for students like mine, what if this kind of activity were built right in to a teacher's day? It would be extremely efficient to have such outings take place during these businesses' open hours *and* have it "count" toward the teacher's work responsibilities. We could make these systems and services that work so singularly act more cooperatively, too. So, why not?

Re-Thinking Teaching Time

Many of the things I did, and still want to do, with my students can take place during a typical school day (at Cosmos the students begin at 7:30 a.m. and go home at 2:00 p.m. but, for simplicity's sake, please feel free to envision whatever school hours you like). Just as many things, though, cannot be done in those hours, especially since some activities that would be meaningful to my students only happen during evenings or weekends. So another thing I propose is a change in the way we use teachers' time. If it were possible for teachers to stagger their schedules and spread them out over different days and times, do you think they would do so? Because I sure would, and I bet Thomas would have been willing to work those days or times that I did not (and vice versa). With such a schedule I could have dropped by Vue Pao's house in the evening to, as needed, guide him as he cooked the family dinner. Or brought the whole class to a theatrical production directed by a local deaf actress. Or shared the recreational (i.e., cultural or sporting events, volunteerism), vocational (i.e., second shift), and domestic (i.e., family resources) opportunities that are only available *after* the average school day has ended. As I argued earlier when I asked us to re-think teaching spaces, I think we must also re-think the times. If we want students to learn how to navigate their world, then we must get out into that world to do so, without being limited to typical "business hours" like the ones operating schools.

Another way I suggest we rethink a teacher's time is possibly my most radical idea, but: what if our responsibility as a teacher did not end the minute a student left our classroom? What if teachers were more like family members, part of a team or "village" of people committed to caring for their MCDHH charges? What if I had re-joined my graduates' lives not as a researcher, but because that was part of my role as a teacher in the United States? Not all graduates will need this kind of follow-up attention (because they may have the people and services they need already in place), but the Camerons and Angels of the world could certainly stand to have me (or someone who knows them and cares about their welfare) drop in to see how they are doing from time to time. What if this kind of long-term advocacy was also built into my teaching responsibilities?

Re-Thinking Research

Earlier in this chapter I argue for the inclusion of MCDHH students and teachers in educational research. I believe this change to include the intended beneficiaries (or at least recipients) of our work could easily change the nature of university-based educational research. To take these ideas a bit further, I will again argue for further blurring of the lines between students, researchers, teachers, study participants, and other contributors to educational knowledge and research. I told you earlier that I regularly tiptoed between the landmines that teacher vs. researcher had become for me, but that I do not see why research, education, and advocacy must remain separate entities. Rather, I argue strongly that combining these systems, coordinating our resources, and behaving more holistically will be beneficial for everyone. If the systems and structures are not in place for teachers or students to be the agents of change, then perhaps the responsibility can begin with researchers.

At the minimum, some implications for research that I would like to see as a result of this study are probably quite obvious: we need to talk much more with MCDHH individuals and their teachers. We need to find out what is important, what is valued, where research can lift burdens or ease struggles, where there are gaps in systems or services, and how we can contribute to a vision of teaching and learning that serves us all. I personally believe I could return to all of my participants and conduct follow up interviews where I might have more directed questions as a result of the thinking I have done since our first visit. I could further clarify their ideas and make certain I have accurately reproduced their messages. At the same time, I would like to add more voices to the conversation, particularly those from students who have fallen out of touch with those of us at Cosmos; what stories could they tell?

Finally, My Final Thoughts

As far as my MCDHH students and graduates go, I have several hopes, multiple things I wish to help make happen. I wish for as much freedom and independence as they can safely manage. I wish for equity in all things, particularly housing, employment, and recreational choices. I wish for strong voices, clear and easy communication, and the luxury of being understood at least most of the time. I wish for equal access, fair and judicious expectations, and the chance to share their strengths and contribute to their families and communities. Perhaps most of all, I wish to take these individuals out of the margins of our culture and society. Because it is there, in the center, that all of my other hopes are more likely to happen.

References

Alabama Institute for Deaf and Blind (2009). Information on deafblindness. Retrieved April 5, 2009 from http://www.aidb.org/Information+on+Deafblindness.aspx?Page=1f27f144 2069-4e68-bd4e-ab692ae724d3.

Andrews, M. (2008). Never the last word: Revisiting data. In M. Andrews, C. Squire, & M. Tamboukou (Eds.) *Doing narrative research* (pp. 86-101). Los Angeles, CA: Sage.

Åsberg, K. K., Vogel, J. J., & Bowers, C. A. (2008). Exploring correlates and predictors of stress in parents of children who are deaf: Implications of perceived social support and mode of communication. *Journal of Child and Family Studies, 17*(4), 486-499.

Baynton, D. C., Gannon, J. R., & Bergey, J. L. (2007). *Through deaf eyes: A photographic history of an American community.* Washington, DC: Gallaudet University Press.

Bell, J. S. (2002). Narrative inquiry: More than just telling stories. *TESOL Quarterly, 36*(2), 207-213.

Bowe, F. G. (1972). Role of the paraprofessional in inner city services to deaf persons. *Journal of Rehabilitation of the Deaf*, 6(2), 120-122.

Bowe, F. G. (2002). Enhancing reading ability to prevent students from becoming “low functioning deaf” as adults. *American Annals of the Deaf, 147*(5), 22-27.

Bruner, J. (1994). Life as narrative. In A. H. Dyson & C. Genishi (Eds.) *The need for story: Cultural diversity in classroom and community.* Urbana, IL: National Council of Teachers of English.

Canagarajah, A. S. (1996). From critical research practice to critical research reporting. *TESOL Quarterly, 30*(2), 321-331.

Carter, K. (1993). The place of story in the study of teaching and teacher education. *Educational Researcher, 22*(1), 5-12 + 18.

Carter, K. (2001). Teaching stories and local understandings. *The Journal of Educational Research*, *88*(6), 326-330.

Cerney, J. (2007). *Deaf education in America*. Washington, DC: Gallaudet University Press.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry*. San Francisco: Jossey Bass Publishers.

Clandinin, D. J., Pushor, D., & Orr, A. M. (2007). Navigating sites for narrative inquiry. *Journal of Teacher Education, 58*(1), 21-35.

Clandinin, D. J. & Raymond, H. (2006). Note on narrating disability. *Equity and Excellence in Education, 39*(2), 101-104.

Clandinin, D. J., & Rosiek, J. (2007). Mapping a landscape of narrative inquiry: Borderland spaces and tensions. In D. J. Clandinin (Ed.) *Handbook of narrative inquiry: Mapping a Methodology* (pp. 35-75). Thousand Oaks, CA: Sage Publications.

Cleave, C. (2008). *Little Bee.* New York: Simon & Schuster Paperbacks.

Cochran-Smith, M. & Zeichner, K. M. (Eds.) (2005). *Studying teacher education: The report of the AERA panel on research and teacher education.* Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Cohen, L. H. (1994). *Train go sorry: Inside a deaf world.* Boston, MA: Houghton Mifflin Company.

Connelly, F. M., & Clandinin, D. J. (2006). Narrative inquiry. In J. Green, G. Camilli, & P. Elmore (Eds.) *Handbook of complementary methods in education research* (pp. 477-487). Mahwah, NJ: Lawrence Erlbaum Assoc. and American Educational Research Assoc.

Council for Exceptional Children (1997). *CEC policy manual, 1997 section three, professional policies, part 1 chapter 3, special education in the schools.* Retrieved May 23, 2010 from http://www.cec.sped.org/AM/Template.cfm?Section=CEC_Policy_Resources1Teplate=CM/ContentDisplay.cfm&ContentID=1449.

Council for Exceptional Children (2010). *Exceptionality areas.* Retrieved May 23, 2010, from http://www.cec.sped.org/Content/NavigationMenu/NewsIssues/TeachingLearningCenter/ExceptionalityArea/.

Darling-Hammond, L. (2006). *Powerful teacher education: Lessons from exemplary programs.* San Francisco, CA: Jossey-Bass.

Darling-Hammond, L. & Bransford, J. (Eds.) (2005). *Preparing teachers for a changing world: What teachers should learn and be able to do.* San Francisco, CA: Jossey-Bass.

D'Zamko, M. E., & Hampton, I. (1985). Personnel preparation for multihandicapped hearing impaired students: A review of the literature. *American Annals of the Deaf,* 9-14.

Easterbrooks, S. R. (1999). Improving practices for students with hearing impairments. *Exceptional Children, 65*(4), 537-55.

Easterbrooks, S. R. (2008). Knowledge and skills for teachers of individuals who are deaf or hard of hearing: Initial set revalidation. *Communication Disorders Quarterly, 30*(1), 12-36.

Ehrmann, M. (2009). *Desiderata.* Scotts Valley, CA: CreateSpace.

Elbaz-Luwisch, F. (1997). Narrative research: Political issues and implications. *Teaching and Teacher Education, 13*(1), 75-83.

Elbaz-Luwisch, F. (2007). Studying teachers' lives and experiences. In D. J. Clandinin, (Ed.) *Handbook of narrative inquiry: Mapping a methodology* (pp. 357-382). Thousand Oaks, CA: Sage Publications.

Evans, C., Stubbs, M., Frechette, P., Neely, C., & Warner, J. (1987). *Educational practitioners: Absent voices in the building of educational theory.* Working paper No. 170. Wellesley, MA: Center for Research on Women.

Ewing, K. M., & Jones, T. W. (2003). An educational rationale for deaf students with multiple disabilities. *American Annals of the Deaf, 148*(3), 267-271.

Fenstermacher, G. D. (2002). A commentary on research that serves teacher education. *Journal of Teacher Education, 53*(3), 242-247.

Fine, M. (1994). Dis-stance and other stances: Negotiations of power inside feminist research. In A. Gitlin (Ed.), *Power and method: Political activism and educational research* (pp. 13-35). New York: Routledge.

Gill, C. J. (2001). Divided understandings: The social experience of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 351-372). Thousand Oaks, CA: Sage.

Greenhalgh, T., & Hurwitz, B. (1999). Why study narrative? *BMJ 3*(18), 48-50.

Groce, N. E. (1985). *Everyone here spoke sign language.* Cambridge, MA: Harvard University Press.

Guardino, C. A. (2008). Identification and placement for deaf students with multiple disabilities: Choosing the path less followed. *American Annals of the Deaf, 153*(1), 55-64.

Hankins, K. H. (2003). *Teaching through the storm: A journal of hope.* New York: Teachers College Press.

Hoffmeister, R. J. (1996). Cross-cultural misinformation: What does special education say about deaf people. *Disability and Society, 11*(2), 171-189.

Humphries, T., Padden, C., & O'Rourke, T.J. (1980) *A basic course in American Sign Language*. Silver Spring, MD: T.J. Publishers.

Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. 33 § 1400 *et seq.* (2004).

Johnson, H. A. (2004). U.S. deaf education teacher preparation programs: A look at the present and a vision for the future. *American Annals of the Deaf, 149*(2), 75-91.

Johnson, J. R., & McIntosh, A. S. (2009). Toward a cultural perspective and understanding of the disability and deaf experience in special and multicultural education. *Remedial and Special Education, 30*(2), 67-83.

Jones, T. W. (1984). A framework of identification, classification, and placement of multihandicapped hearing-impaired students. *The Volta Review, 86*(3), 142-151.

Jones, T. W., Jones, J. K., & Ewing, K. M. (2006). Students with multiple disabilities. In D. F. Moores and D. S. Martin (Eds.), *Deaf learners: Developments in curriculum and instruction* (pp. 127-143). Washington, DC: Gallaudet University Press.

Kincheloe, J. L. & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research, 3rd edition (*pp. 303-342). Thousand Oaks, CA: Sage Publications.

Kisor, H. (1990). *What's that pig outdoors? A memoir of deafness.* New York: Hill and Wang.

Kluwin, T. N., McAngus, A., & Feldman, D. M. (2001). The limits of narratives in understanding teacher thinking. *American Annals of the Deaf 146*(5), 420-428.

Knoors, H. & Vervloed, M. P. J. (2003). Educational programming for deaf children with multiple disabilities: Accommodating special needs. In M. Marschark & P. E. Spencer (Eds.), *The Oxford Handbook of Deaf Studies and Deaf Education* (pp. 82-94). New York: Oxford University Press.

Komesaroff, L. (2008). *Disabling pedagogy: Power, politics, and deaf education.* Washington, DC: Gallaudet University Press.

Lennon, J. (1971). Imagine. On *Imagine* [CD]. Hollywood, CA: Capitol.

Luckner, J. L., & Carter, K. (2001). Essential competencies for teaching students with hearing loss and additional disabilities. *American Annals of the Deaf, 146*(1), 7-15.

Luckner, J. L., Muir, S. G., Howell, J. J., Sebald, A. M., & Young, J. III (2005). An examination of the research and training needs in the field of deaf education. *American Annals of the Deaf, 150*(4), 358-368.

Marschark, M., Lang, H. G., & Albertini, J. A. (2002). *Educating deaf students: From research to practice.* New York: Oxford University Press.

Marschark, M. & Spencer, P. E. (Eds.) (2003). *Oxford handbook of deaf studies, language, and education.* New York: Oxford University Press, Inc.

Meadow-Orlans, K. P. (2001). Research and deaf education: Moving ahead while glancing back. *Journal of Deaf Studies and Deaf Education, 6*(2), 143-148.

Moores, D. F. & Martin, D. S. (Eds.) (2006). *Deaf learners: Developments in curriculum and instruction.* Washington, DC: Gallaudet University Press.

National Center on Severe and Sensory Disabilities (2010). Outcome data for students with low-incidence disabilities, 2006. Retrieved May 23, 2010, from http://www.unco.edu/ncssd/resources/StatOutcomes.shtml.

No Child Left Behind (NCLB) Act of 2001, 20 U.S.C.A. § 6301 *et seq*. (West 2003).

Nolan, A. L. (2009). The content of educational psychology: An analysis of top ranked journals from 2003 through 2007. *Educational Psychology Review, 21*(3), 279-289.

Padden, C. & Humphries, T. (1988). *Deaf in America: Voices from a culture.* Cambridge, MA: Harvard University Press.

Pavlenko, A. (2002). Narrative study: Whose story is it anyway? *TESOL Quarterly 36*(2), 213-218.

Pinnegar, S., & Daynes, J. G. (2007). Locating narrative inquiry historically: Thematics in the turn to narrative. In D. J. Clandinin (Ed.) *Handbook of narrative inquiry: Mapping a methodology* (pp. 3-34). Thousand Oaks, CA: Sage Publications.

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences.* Albany, NY: State University of New York Press.

Reiman, J., Bullis, M., & Davis, C. (1992). *Assessment, intervention, and program needs of lower achieving and multiply disabled deaf people requiring extended transition support*. DeKalb, IL: Northern Illinois University Research and Training Center on Traditionally Underserved Persons Who Are Deaf. (ERIC Document Reproduction Service No. ED356601)

Repetto, J. B. (2003). Transition to living. *Exceptionality, 11*(2), 77-87.

Reyes, A. (2007). *Language, identity, and stereotype among South Asian American Youth: The other Asian.* Mahwah, NJ: Lawrence Erlbaum Associates.

Roberge, M. M. (2003). *Generation 1.5 immigrant students: What special experiences, characteristics, and educational needs do they bring to our English classes?* Paper presented at the Thirty-seventh Annual TESOL Convention, Baltimore, MD. Article retrieved from http://www1.american.edu/tesol/Roberge_article.pdf.

Rodda, M. & Eleweke, C. J. (2002). Providing accessible services to minority ethnic deaf people: Insights from a study in Alberta, Canada. *American Annals of the Deaf, 147*(5), 45-55.

Schwind, J. K. (2003). Reflective process in the study of illness: Stories as experienced by three nurse teachers. *Reflective Practice, 4*(1), 19-32.

Senghas, R. J. & Monaghan, L. (2002). Signs of their times: Deaf communities and the culture of language. *Annual Review of Anthropology, 31*, 69-97.

Shulman, L. S. (1986). Those who understand: Knowledge growth in teaching. *Educational Researcher, 15*(2), 4-14.

Spencer, P. E., & Marschark, M. (2010). *Evidence-based practice in educating deaf and hard-of-hearing students*. New York: Oxford University Press.

Steeves, P. (2006). Sliding doors–opening our world. *Equity & Excellence in Education, 39*, 105-114.

Stephey, M. J. (2008). Gen-X: The ignored generation? [Electronic Version]. *Time,* Article 08599173152800. Retrieved February 16, 2010 from http://www.time.com/time/arts/article/0,8599,1731528,00.html.

Swanson, C.B. (2008). *Special education in America: The state of students with disabilities in the nation's high schools.* Bethesda, MD: Editorial Projects in Education Research Center. Retrieved November 27, 2008 from www.edweek.org/media/eperc_specialeducationinamerica.pdf.

Swiller, J. (2007). *The unheard: A memoir of deafness and Africa.* New York: Henry Holt and Company.

Wheeler-Scruggs, K. (2002). Assessing the employment and independence of people who are deaf and low functioning. *American Annals of the Deaf, 147*(4), 11-17.

Whelan, E. M., & Kretschmer, R. E. (1996). Hearing-impaired students with multiple disabilities as people who think, communicate, and feel. *Volta Review 98*(5), (n.p.).

York-Barr, J., Sommerness, J., Duke, K., & Ghere, G. (2005). Special educators in inclusive education programmes: Reframing their work as teacher leadership. *International Journal of Inclusive Education, 9*(2), 193-215.

Young, A., & Tattersall, H. (2005). Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education, 10*(2), 134-145.

Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood: Insights from families with disabled children in Norway. *Disability & Society, 23*(6), 625-636.

Zeichner, K. (1995). Beyond the divide of teacher research and academic research. *Teaching and Teachers, 1*(2), 153-172.

Zumwalt, K. & Craig, E. (2005). Teachers' characteristics: Research on the demographic profile. In M. Cochran-Smith & K. M. Zeichner (Eds.) *Studying teacher education: The report of the AERA panel on research and teacher education.* Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Appendix A: Pre-planned Interview Questions

Participant Pseudonym:
Interview date:
Length of interview:

1. Tell me anything; who are you?
2. Historical topics (where born, family structure)
3. Home: communication, current living situation
4. Hearing loss (degree of) and impact of that (if any is perceived); any other topics central to ability, special services, accommodations, etc.
5. Schools attended (and then multiple questions about their schooling including much of what is suggested in the assent)
6. Post-secondary training? Why/why not?
7. Free time interests, friendships, other "daily living" topics
8. Future goals, career or job interests, how these are/are not perceived to be linked to school
9. What they recall/what stands out about their school experiences (classes, teachers, learning, friends, socialization, extra-curriculars)
10. What they learned in school that has been most helpful now they're out of school (as well as the inverse: what did they learn that was not useful?)
11. "Tell me about a time when you felt really happy at school. What happened then?"

12. “Tell me about a time when you were excited about learning – what did you learn? Why was it exciting?”

13. “Do you remember something that was hard for you to learn? How did you learn it? Who helped you?”

14. “Who were your favorite teachers? Why were they your favorites?”

15. “Did you think something was harder for you because you were D/HH? Was something easier because you are D/HH?”

16. “Did/do you use ALDs (assistive listening devices)? Why/why not? Do you think they made a difference for you?”

17. “Did you get extra services (i.e. speech/language, social work)? Did you like working with those people? Why/why not?”

18. “What did you like about school? What didn’t you like? Why? Can you give me examples?”

19. “If you ran a school, what would you change? What would you keep the same?”

20. “Some people communicate/d with hearing people by writing notes with them, how did you talk to people who were not deaf or hard of hearing?”

21. Do you have any questions, comments, other things to share?

22. Would you like to tell me any other story?

Appendix B: Participant Assent Form

Note: This form is written in language typical of MCDHH individuals; it is easier to understand for the graduates who may want to read or review it on their own (the language in this form more closely mirrors the syntax of American Sign Language). The form will be explained as often as necessary by someone familiar with the student's communication mode (probably the PI). Both the researcher and participant will receive a signed copy of this form for their records.

Telling Our Stories: LD's Book

LD* wants to talk to you and ask you questions if okay. Your stories will collect; write with other kids their stories, and put in a book for other people to read. This is LD's "research" (will need to give that sign and maybe explain it a little) she is doing at the University.

Maybe tell about (some ideas):

- School and your different schools (where, for what grades)
- Teachers (who, what taught) and other staff (who, what do)
- Classes you had (what remember, what enjoyed, what hated)
- What you learned – what do you know how to do? What you wish you learned? Want more time for school?
- Who were your friends? Were they D/HH, too? If they were hearing, how did you communicate with them? Why did you like them? What did you do together? Who were not your friends? Were there mean kids at your school? How do you know?
- What is it like at your house? What do you do (for fun, for chores)?
- Do you have a job? Where? What do? You like? You have other jobs?
- You deaf ... hard of hearing ... which? You use CI? Hearing aids? You talk? Sign? How communicate with hearing people?

Will you also:

- Be in pictures (photos) or videos? Y or N
- Let use your old school homework or make copies share? Or maybe new writing? Y or N

LD will always ask before taking your work or your picture and you can always say no.

Writing your name means: It is okay. I want to talk to LD. She can use my work and stories. I will say “no” or “stop” when I don’t want to tell more, don’t want to join in. That is okay and I understand I will not have consequences if I want finished.

Student Name/Signature: ______________________________Date: __________

Name/role of person explaining this form: ___________________Date:________

**LD is my name sign; most of these students recognize it best as the letters “L D” are often voiced while my name is signed. Some students recognize my first name, Lisa, in writing as well, but my last name often, and quite understandably, confounds them.